THE DEAF-BLIND MINORITY: AN OVERVIEW

A thesis submitted in partial satisfaction of the requirements for the degree of Masters of Art in

Education, Educational Psychology
Counseling and Guidance

by

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The undertaking of this project is the culmination of a long-held ambition to contribute to the promotion of a more accurate and realistic understanding of deaf-blindness in general, and deaf-blind people in particular. My awareness that such elucidation is necessitated is based on experience, both personal and vicarious. On the basis of the insight acquired as a member of the deaf-blind minority, it is my contention that only through the elimination of erroneous ideas, often coupled with apprehension currently rampant within our society, will it be possible for deaf-blind individuals to realize their rightful place as unique members of the human family.

Literature pertaining to research directly relevant to deaf-blindness is scant. Consequently, on the premise that deaf-blind individuals themselves are, generally speaking, the most valid source of insight into the salient aspects of deaf-blindness, I have, in several instances, utilized material which they have published. Since I have experienced many of the problems they discuss and confronted issues debated, it is not unlikely that my presentation falls short of complete objectivity. From my perspective this is a small price to pay for the challenge to promote an awareness of 30,000 unique human beings who happen to be deaf-blind and are in need of
empathy -- not pity -- constructive assistance -- not stifling dependency.

Helen's books are prized today,
Their message ringing clear:
That mind and soul can reach great heights
Though one can't see or hear;
The message which she left to us
Who are both deaf and blind,
Is symbolized in hope
That life need not leave us behind.
If people would accept us
As unique works of God,
To use what gifts He's left us,
Then life would not be hard;
When given opportunity
To learn and love and live,
We'll take the road which Helen paved,
For we too need to give.

(From HAIL TO OUR LEADER by K.C. Spear)
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ABSTRACT

THE DEAF-BLIND MINORITY: AN OVERVIEW

by

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Masters of Arts in Educational Psychology

At this point in time, there are approximately 30,000 persons in the United States who are classified as deaf-blind. A review of research literature indicates that scant attention has been centered on this minority. One salient aspect of this situation is that, for the vast majority of the general public, knowledge of deaf-blindness is basically limited to identification with the life and works of Helen Keller. That such a limited base of knowledge is misleading is validated by significant variables which include 1) onset of deaf-blindness, 2) severity of disability and 3) etiology. Equally significant as compared to Miss Keller's ongoing life experience pertain to lifestyle; advances in occupational
opportunities; and technological advances which promote a higher level of independence. The primary objective of this thesis is to provide enlightenment in these areas, which considerable emphasis on the psychological implications. In an effort to promote understanding, an effort is made to provide insight as to how deaf-blind persons utilize their remaining senses and other compensatory alternatives. Finally, enlightenment is presented on the various communication methods used by the deaf-blind in their effort to cope with challenge of avoiding isolation from people and/or knowledge.
THE DEAF-BLIND MINORITY: AN OVERVIEW

CHAPTER I

Introduction

No two people have contributed more to the field of the deaf-blind than Helen Keller (1880-1967) and her "Teacher"- companion Anne Sullivan Macy (1866-1936). Each, having been immortalized in book, on stage and screen, is a legend in her own right. Whatever their plight or outlook may be, the debt we who are deaf-blind owe these two women can never be over-rated. That is to say, that through their efforts they awakened in our society, if not mankind as a whole, the realization that through education and other constructive efforts, it is possible for deaf-blind individuals to become useful, integrated members of humanity. However, there is an imperative need on the part of professionals in particular, and society in general, to acknowledge overtly, that every deaf-blind person --like all other mortals -- are unique individuals. In point of fact, the major objective of this paper is to elucidate irrefutably that, even within the nexus of impaired sight and hearing which bind an individual to the deaf-blind minority in totem, there are distinct variables.

Explicitly, what this means is that, in order to assist a deaf-blind person in a professional capacity, necessi-
tates the assimilation of knowledge concerning such
differentials as:

1. **Etiology, i.e. Cause of Disability**

   In the case of Helen Keller, cause of disability is
attributed to an undiagnosed illness. In other cases it
has been established that illnesses (or diseases) such as
meningitis, scarlet fever and rubella have left victims
both deaf and blind. Other causes are 1) Hereditary
factors--e.g., retinitis pigmentosa; Usher's Syndrome.
2) Degenerative process of aging. 3) Accidents.

According to statistics provided by the HELEN
KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS
(1982), there are currently between 20 and 30 thousand
"legally" deaf-blind persons in the United States. Of
this number, ten thousand are under the age of twenty-one.
At this point in time, according to the same source,
Ushers Syndrome is considered the major cause of deaf-
blindness. As defined by the HELEN KELLER NATIONAL CENTER
(HKNC), this condition (often referred to by the letters
US) is defined as follows:

"A (heredity) condition characterized by congenital
deafness and retinitis pigmentosa, which causes
night-blindness and a gradual narrowing of the
visual field that may result in total, or nearly
total loss of vision."

Rubella (German measles) is the second most prevalent
cause. What occurs, is that a woman contracts Rubella
during pregnancy, the virus attacks the fetus, resulting
in impaired hearing and/or vision; and, in some instances, brain damage is an additional consequence.

2. Onset, i.e. Age at Which the Individual Becomes Deaf-Blind.

This variable is of tremendous significance from the developmental and psychological perspective. That is to say, the individual who, like Helen Keller, becomes deaf-blind before the age of five is exposed to a different set of problems related to physical, intellectual and emotional development than those confronting the individual who becomes deaf-blind during adolescence or adulthood. Similarly, the individual who is congenitally blind and adventitiously deaf. Bearing all of this in mind, it follows that the developmental process of the congenitally deaf-blind is an entirely different matter than the adjustment process required of the adventitiously deaf-blind adolescent or adult.

With regard to ontogeny, no comparison is more poignant than that between the congenitally deaf-blind and, in point of fact, any other category of deaf-blind persons. This statement is clearly adduced in an address by Dr. McKay Vernon, renown educator and writer in the field of the deaf and deaf-blind. Speaking before the Seventh National Convention of the American Association of the Deaf-Blind, he states,
"Most persons who are born deaf-blind are victims of prenatal rubella. Psychologically, their plight is dramatically different from that of almost all other deaf-blind people because they suffered the double loss before having gained the tremendous amount of knowledge those who have sight or hearing a few hears have gained. I know of no person born deaf-blind who has even been able to overcome this awesome deprivation and achieve a basic competence in reading, writing, or sign language. In other words, none have attained basic communication. Thus, they face almost total isolation from people, ideas and knowledge." (Vernon, 1982, p.3)

In addition to the need to adjusticate the situation of each deaf-blind individual in the light of the variables mentioned above, it is essential to recognize that: 1) few, if indeed there are any deaf-blind persons have, like Helen Keller lived from the time they became disabled until death in the presence of a full-time companion. (As a matter of fact, there is considerable controversy as to whether such a relationship is beneficial or detrimental.) Suffice it to say that no valid opinion can be formulated without a realistic appraisal of certain facts related to Helen Keller's life. First, she was born in 1880 in Tuscumbia, Alabama -- an agrarian community. Her mother, Kate Keller, as mistress of the household had neither the time or the know-how to give her deaf-blind daughter, the supervision and guidance which was eventually provided by Anne Sullivan. Ample proof of the accuracy of this statement lies in the fact that, when Ms. Sullivan arrived at the Keller home
in March 1887, she found her charge to be undisciplined and unmanageable. It is also imperative to bear in mind that, from the age of nineteen months Helen's loss of both sight and hearing was total. Given these circumstances and speaking as a deaf-blind person who has taught deaf-blind children and adults, I cannot imagine how Ms. Keller could have achieved the level of intellectual and emotional development she realized without the constant support and assistance of Ms. Sullivan and her successor Polly Thompson. Any interested reader will find many statements in books written about and by Helen Keller to vindicate this conclusion. One example is found in a letter which author Mark Twain wrote to Ms. Keller in 1902:

"You are a wonderful creature, the most wonderful in the world. You and your other half together--Miss Sullivan I mean -- for it took the pair of you to make a complete and total whole."

(Keller, 1905; Lash, 1980).

Another factor which must be dealt with honestly and realistically is that through stereotypical and prejudicial attitudes, society places a psychological burden on the deaf-blind individual which, without support and encouragement from a significant other results in withdrawal as opposed to self-actualization. The crux of the matter is, in my estimation, not whether a deaf-blind person should have a companion but rather, how such a person is motivated. I believe the reader
will concede that when such a relationship exists, the motive of the companion should be to complement rather than dominate the deaf-blind individual. If we take Mark Twain's statement at face value, it would indicate that Anne Sullivan (Macy) succeeded beyond measure.

There is a statement made by Helen Keller at the age of fourteen which clearly indicates her awareness of the precise time when she arrived as Miss Sullivan's equal, ".....and she (Anne Sullivan) ceased to treat me as a child. She did not command me anymore."

One of the most difficult tasks confronting anyone who has an intimate relationship with a deaf-blind person consists of the ceaseless effort to enable such a person to be a vital part of all that is happening around them. Miss Sullivan's knowledge of, and efforts in this regard are verified in a quotation from her biographer Nella Braddy (Henny). The quote taken from HELEN AND TEACHER, by Joseph P. Lash reads, in part,

"Teacher's (Anne Sullivan) great fascination to women as well as men: it was Teacher rather than Helen who attracted John Macy, Phil Smith, Dr. Neilson and Ned Holmes, all of whom learned the manual alphabet so as to talk with Helen. Teacher never left Helen out, never allowed anyone else to leave her out; as long as she lived she kept encouraging other people to use the (manual) alphabet and she
was always ready to turn Helen over to anyone capable of spelling to her."

All of the men mentioned above became intimates of Anne and Helen's during the latter's Radcliffe days. The former became Mrs. John Macy in 1904; they were divorced ten years later.

During the almost twenty-one years that preceded her arrival at the Keller home in 1887, Anne Sullivan had experienced much that would prove valuable for the role for the rest of her life. Poor vision had plagued her for as long as she could remember. Albeit surgery performed at fifteen had enabled her to read, the threat of near or total blindness would recur and become a reality during her last years. Consequently, it is not surprising that she used every means within her power to make the visual world as real as possible for Helen.

In addition, her ability to empathize with Helen's estrangement from the world in which she lived was intensified by her own four years of confinement within the walls of the state almhouse. Then, there was her little brother, Jimmy, who arrived at the almhouse with her only to die shortly thereafter. She would never forget the loneliness which engulfed her. At this point, she became determined to break the shackles that seemed destined to bind her to a life of ignorance and poverty. At fourteen, with no previous schooling, she
entered the Perkins School for the Blind; and, in six years completed the requirements for graduation at the top of her class. Rather than break her, adversity had helped mold her into a woman of intelligence, courage and determination, with a longing to fill the void in her heart and life imposed by her orphaned state. Explicitly her commitment or dedication to Helen Keller was one of choice and, the need of one for the other was mutual. I would surmise that in the process of fulfilling these mutual needs, in a spirit of love and respect, the relationship was complementary.

The Psychology of Deaf-Blindness

The most salient aspect of the lives of Helen Keller and Anne Sullivan as it affects the deaf-blind of today, is the tendency of all but the most enlightened to assume that every deaf-blind person has a similar background and lifestyle. It can only be hoped that, through the discussion presented thus far the reader is beginning to perceive the situation more realistically. In summation, the crucial issue in this process is awareness of the significance for each deaf-blind individual of the cause, onset, and severity of deaf-blindness. Furthermore, from the psychological perspective, the above mentioned factors are crucial to in the comprehension of the most meaningful and descriptive aspect in the psychology of deaf-blindness. The aspect to which I refer is
called "isolation". On the one hand there is the isolation from people and the all important ability to share feelings such as joy, anger and love. As the reader will concede the sharing of such feelings is essential to emotional development and mental health. On the other hand, there is cognitive isolation -- i.e. the isolation from knowledge and ideas. The essence of the problem in either case is communication. For this reason, the problem or degree of deprivation is epitomized in the individual who is congenitally deaf-blind. According to authorities in the field of the deaf-blind, there is no record of any such individual who has mastered language to literacy. Consequently, the brain as a tool in relating to the world around them is of limited use. This means a congenitally deaf-blind person relies, sometimes exclusively, on the fragmented information assimilated through the senses of smell, taste, and touch.

Before proceeding further, I believe a definition of "deafness" and "blindness" is in order. At this point in time, the most widely used source of information pertaining to the deaf-blind is the HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS, a pre-vocational rehabilitation facility located at Sands Point, New York. This facility frequently referred to by the letters AHKNC uses the following definitions in determining
the eligibility of an individual for its services:

**Deafness:** A physiological hearing impairment so severe that most speech cannot be understood through the ear or with optimum amplification.

**Blindness:** Visual acuity not exceeding 20/200 in the better eye with correcting lenses, or visual acuity greater than 20/200 if the visual field is constricted to twenty degrees or less (i.e., severe tunnel vision).

Whatever has been said, or remains to be said in this thesis, the reader's ability to imbibe the full implications of the above definition of deafness is the fact that albeit some deaf-blind are totally deaf, others can understand some (but not most) through the ear or with amplification provided by one -- and often two -- hearing aids. And, implicit in the definition of blindness is the fact that some deaf-blind persons are totally blind, some have good vision by a constricted visual field; plus, the many who fall between the two extremes.

From the psychological perspective, in addition to the implications of the preceding definitions, it is equally imperative for the reader to know that, in many cases, onset of deafness and blindness do not occur simultaneously. Age of onset of each disability is directly related to the adjustments to be made by the
individual. Furthermore, this factor is equally important in regard to isolation mentioned earlier, and described by Dr. McCay Vernon as "the overwhelming pervasive factor in a psychology of deaf-blindness."

(Vernon, 1982, p.2.) Implicitly this means that adjustment to deaf-blindness varies according to age of onset of the loss of hearing and the age of onset of the loss of vision. That is to say, was deafness or blindness congenital; if one was congenital, and what age did the onset of the second occur; if both disabilities were adventitious, at what age did onset occur? That these etiological factors are tremendously significant psychologically stems from the fact that, to a great extent, they determine the experiential and coping abilities which the individual will utilize in coping with his/her isolation from human and intellectual stimuli. Of equal importance is the fact that age of onset of deafness and blindness is a determinant as to the psychological trauma, or "grief" experienced with the loss. In order to facilitate a more accurate understanding of what is involved, let us examine briefly some of the variables.

First, let us consider the person who is congenitally blind and adventitiously deaf. On the other hand, having already adjusted to blindness, such an individual knows Braille, usually has acquired mobility and other
daily living skills, has a command of English, and (at least at the onset) retains the ability to speak. On the other hand, such an individual attempts to compensate for the loss of vision by utilizing their auditory sense to the fullest. Since the sense of hearing, to a blind person, embodies the major link to the world and life, it should not be hard for anyone to empathize with the depth and intensity of the trauma experienced through its deprivation. Functionally, the major psychological factor is the resultant isolation from people. That is to say, that although the individual has the necessary expressive skills to communicate with people the only available means of receptive communications are a) a mechanical device known as a "Teletouch", which utilizes Braille; or b) if the person knows print, print-on-palm, which requires practice and patience before it can be used with any amount of speed. To learn fingerspelling (the Manual Alphabet) necessitates the assistance of instruction which is not readily available. Of course, the individual still has access to ideas and knowledge via Braille, and, in some cases, print using an electronic reading device called an Optacon. (TSI, 1972, pi)

In an effort to acquaint the reader with the wide spectrum of communication modalities available to blind, adventitiously deaf, I draw upon research and experience. Anyone familiar with the deaf community knows that sign
language is widely acclaimed as the most desirable mode of communication, I would like to cite a statement of Helen Keller's to the contrary. The quotation is taken from a letter written in June 5, 1899,

"Well, I must confess, I do not like the sign language, and I do not think it would be of much use to the deaf-blind. I find it very difficult to follow too rapid motions made by the deaf-mutes, and besides, signs seem a great hindrance to them in acquiring the power of using language easily and freely...."

For the benefit of the reader who, considering the changes which have occurred during the past 40 years of fifty years, may feel that, though interesting, Miss Keller's views seem obsolete, I offer a more recent source from the deaf-blind community in the person of the late Richard Kinney (1923-79). (In all due respect to Miss Keller, however, there is another poignant reference in the same letter:)

".....At any rate, I am sure the deaf-blind cannot learn to use signs with any degree of facility."

(Keller, 1905, p. 178).

It is imperative to note that, so far as available research is concerned, I have been unable to verify any suggestion related to any instruction in sign language received by Helen Keller. Under penalty of conscience,
I am also obliged to state that there is, to my knowledge, no record indicative of sign language instruction for Dick Kinney either. However, I can state positively that Dick Kinney wrote the first comprehensive text dealing with the problem of living with deafblindness.

Concerning communications, the above mentioned communication skills are cited; other communication modalities, such as the alphabet glove and Morse Code; but sign language as a desirable alternative is never mentioned. To this I would for whatever it is worth add this, as a deaf-blind person with a keen desire to reach all deaf-blind people with whom I come in contact, I have earnestly endeavored to master sign language during the past three years, concentrating on signed English (SEE) as opposed to American Sign Language (ASL). Whereas the former utilizes the components of the English language, the latter is a separate and distinct language. The two major difficulties confronting a student of sign language who is totally blind or 1) the inability of most, including people who are fluent in sign language, to use signs tactally with any degree of facility; 2) the sufficient opportunity to practice. However, within the past three decades, schools such as the Perkins School for the Blind, the pioneer in the education of deaf-blind, are offering sign language instruction to students. For the present group of congenitally blind adventitiously deaf
adults however, can state on the basis of a survey that I conducted at the Seventh Open Convention of the American Association of the Deaf-Blind -- Greeley, Colorado, 1982 -- that the preferred communication modalities are 1) finger spelling, 2) the Teletouch and 3) Tadoma.

**Congenitally Deaf Adventitiously Blind**

Of the approximate 20,000 deaf-blind adults in this country the largest number consists of individuals who were either born deaf or became deaf at an early age. Of this number, over half have a genetic disorder known as Ushers Syndrome. Victims of Ushers Syndrome usually receive their basic education in a program designed for the deaf. This means, as a rule, they learn finger-spelling and are fluent in sign language. Visual loss, attributed to Retinitis Pigmentosa, is progressive, and can begin as early as the late teens or as far along in life as middle age. With regard to the psychological factor of isolation a victim of Ushers Syndrome (US) has two advantages. First, he/she is already proficient in finger spelling and sign language and is therefore to communicate -- at least with people who share these skills such as the deaf, some deaf-blind and some hearing people -- thus eliminating to some extent the isolation from people. Also, since most US victims retain some vision, they are able to continue reading print with the use of
an electronic device called a Visual-Tech. The total psychological adjustment is often less traumatic because visual deterioration occurs over a period of from 20 to 60 years. For the individual whose ties with the deaf community remain close, much emotional support is available. Equally important is the fact that many such victims have married and have a family before loss of vision occurs. On the whole, they are much more fortunate than deaf people whose loss of vision is due to other etiological factors, such as diabetic retinopathy, glaucoma or cataracts. For the diabetic the psychological trauma is intensified by the fact that partial vision can return and disappear more than once so that prognosis remains uncertain. That such individuals often experience periods of acute anxiety is not surprising. It is not unusual for such an individual to have suicidal tendencies. Albeit such individuals usually have the communication skills necessary to avoid isolation from people -- i.e., the same skills as an Ushers Syndrome victim -- they are often inadequate as a means of alleviating trauma.

**Congenitally Deaf-Blind**

It has already been stated earlier in this Chapter that, from the psychological perspective, this segment of the deaf-blind minority, by virtue of their inability
to master the necessary communication skills is destined from birth to a life of total, or near total, isolation from both people and information. Of those in this category at the present, the majority are victims of prenatal Rubella (German measles). In addition to the fact that, when the Rubella virus infects the embryo partial or total loss of vision and hearing occur there is often further damage resulting in a third (or even fourth) disability, such as mental retardation. Many such persons require lifelong care; and, most never experience a close relationship with another human being. It stands to reason that for Rubella victims who retain some residual vision and/or hearing, the situation is not as tragic.

Adventitiously Deaf-Blind

For the child who becomes deaf-blind after the acquisition of spoken language, the psychological adjustment, though traumatic, is somewhat easier than for the individual who experiences deaf-blindness after reaching adulthood. On the one hand, the adult has assimilated more knowledge, formulated for relationships. On the other hand, especially if the environment is supportive, the need to master a new communication modality for receptive purposes is usually not as traumatic. In either instance, however, complexity of the psychological factors involved is hard to imagine, let alone describe.
The reader will concede that loneliness is experienced by most people at some point in their lives. If this can be said of individuals with all their faculties, it should not be difficult to comprehend the fact that loneliness is an inherent aspect of the deaf-blind person's isolation from people. During an address before the World Council on the Welfare of the Blind, in 1959, the late Richard Kinney, who had entered the world of the blind as a child and world of the deaf-blind in his early twenties deals with the subject of loneliness as follows:

Is it being snowbound alone in an icy mountain cabin on a winter night while the wind shrieks outside? Is it drifting alone in an open boat on an empty sea, with only the moon and stars for company? No, true loneliness these. True loneliness is sitting in a warm comfortable room filled with talking, laughing people and feeling yourself cut off-- absolutely cut off -- from all that frienliness and companionship because you are deaf and blind and not one person in the room knows how to communicate with you."

(Crist, 1974, p. 71).

Conclusion

In the foregoing pages an effort has been made to present the reader with a realistic picture of the deaf-blind minority. At the core of this picture is the
role which etiology and age of onset of the double deprivation plays in the ongoing life process of each individual. These factors have a direct relationship to the degree of isolation from information and/or people which is the most significant concept in the psychology of deaf-blindness. In the following chapters this picture will, hopefully, be enlarged to include actual case histories of deaf-blind individuals from each of the categories within the minority -- i.e. congenitally blind adventitiously deaf, congenitally deaf adventitiously blind, adventitiously deaf-blind, and congenitally deaf-blind.

However, there is one aspect of psychology of deaf-blindness of which the reader should be aware. I am referring to the fact that the deaf-blind minority tends to be factious. That is to say that, the congenitally deaf are oriented toward the deaf community, while the congenitally blind and adventitiously deaf-blind are oriented toward the hearing community. In each instance, the deciding factor is communication preference. For the deaf individual the preference, as has already been mentioned, is sign language; for the blind the preference is for communication skills which utilize English. It goes without saying that each faction believes their preference to be the best for all deaf-blind people. Albeit there are advantages to each with even more for a combination of both, I believe that the only preference
is the one with which each deaf-blind person is most comfortable.
CHAPTER II
A CHALLENGE OR A CROSS

The reaction of parents on learning that their child is handicapped at birth, or as the result of disease or accident is one of shock and despair. If this can be when the child has a single handicap, how much greater the trauma must be when the child has a multiple handicap such as deaf-blindness. Often the situation is compounded by the fact that the parents have no idea of where to turn for help. Within the past fifteen years it has become clear, through specialized programs such as "Infant-stim", that the handicapped child's development is improved when parents receive constructive guidance in dealing with helping their child from infancy. (Pines, 1982). Some programs of assistance to parents and their handicapped children began as demonstration projects under the Handicapped Children's Early Education Assistance Act of 1968. In addition to the psychological effects, by placing the center of infant development in the home and encouraging parents to become directly involved, the child's development is stimulated through the process of constant reinforcement. This positive approach was given further impetus through the passage in 1975 of the Education of All Handicapped Children Act, which made it illegal for State and local schools to
exclude handicapped from schools. It can be stated with emphasis that the realization of the need to work with the family rather than with the handicapped child as a separate entity is of tremendous significance. For example, a young teacher of special education in a local high school has five teenagers in her class who are Rubella victims and are legally deaf-blind. Most of her teaching involves instruction in daily living skills. Progress is often nil, because parents are not reinforcing at home what their child is being taught at school. As this teacher states:

"The parents have the wrong attitude. They treat their handicapped kids like babies. Its frustrating and sad. I really think the parents need help as much as the kids do but there is nothing available not even from school counselors."

Albeit progress has been made, there remains, as the comment above indicates an urgent need for qualified counselors in all disciplines -- e.g., marriage, family, school -- to assist deaf-blind individuals and their families in their struggle to accept and cope with the complexities inherent in the life process.

As the reader is no doubt aware, there is a general consensus among different schools of psychotherapy as to the importance of the early years on personality development. Basically, differences in personality theories
concerns how such development is brought about, and motivation. For example, Carl Rogers' personality theory emphasizes the importance of experience, declaring it to be "reality" to the growing child. Motivationally, this theory postulates the tendency, from infancy, toward self-actualization, which is defined as

"The inherent tendency of the organism to develop all its capacities in ways which serve to maintain or enhance the organism." (Rogers, 1959, p. 196.)

On the other hand, Individual Psychology takes the view that the primary motivational force, which is innate as potentially is a cognitive striving to belong, to be significant (Adler, 1967). On the basis of experience, the child formulates biased apperceptions which are subjective evaluations rather than objective reality (Grunberger, 1948). Albeit the convictions developed by the individual may be categorized in many ways, for the purpose of this discussion, the following are used,

1. The self concept -- the convictions I have about who I am.

2. The self-ideal, coined by Dr. Alfred Adler in 1912 is the convictions of what I should be or am obliged to be in order to have a place in the schism of things.

3. The not-self -- convictions about the world, people nature, and what the world expects of me.
4. The ethical convictions -- the personal code of "right" and "wrong".

When a discrepancy between the self and the ideal self convictions arise "I am blind (deaf); I should be sighted (hearing)" -- and the convictions are "central to our sense of existence" (Allport, 1960,) inferiority feelings also known as feelings of inadequacy ensue.

Stated succinctly, lack of congruence between the self-concept and convictions concerning the the not-self or in the moral realm, usually result in feelings of inferiority. No doubt the reader will concede that, in the course of a lifetime, most of us experience feelings of inferiority. It is only when we come to believe that we actually are inferior, thus developing an "inferiority complex", that we thwart our own efforts towards self-actualization and, if we are parents, those of our children. For example, the mother of a Rubella victim knows that her child's disability is directly related to her bout with German measles during pregnancy. If she is plagued by feelings of guilt -- a variant of the inferiority feeling (Adler, 1926)-- the handicapped child, the whole family for that matter, can be adversely affected. Similarly, both partners in a marriage between first cousins, even though unaware of the danger until they learn at the birth of a handicapped child that the cause
is genetic, often suffer intently from guilt feelings. No one can fail to acknowledge the courage and strength it takes to surmount such feelings. The absence of both these qualities usually has a disastrous effect not only on the personality development of the deaf-blind, or handicapped child, but on the stability of the family as well. On the basis of personal experience plus the experiences of other deaf-blind persons, I share Alfred Adler's view that the individual cannot be studied in isolation, but must be studied holistically. Inherent in the holistic study is the inclusion of the family. The family in turn, has, within the past decade, come to be viewed by many as a "system". By way of clarification, the "system" is defined as,

"Any entity the parts of which co-vary interdependently with one another, and which maintains equilibrium in an error-activated way." (FAMILY CRUCIBLE, p.46).

The experience of Laura and her family, related below, clearly illustrates this point.

Laura. Laura is a Rubella victim with two older siblings, Janie and Doug. Both children were in nursery school when their mother became pregnant with Laura. The mother held a part-time job in the neighborhood. Since she was not under the care of a physician at the time of her bout with German measles, she did not know the virus could attack the unborn fetus. Despite all efforts to
reassure her, the mother blamed herself for Laura's disability. Laura was legally deaf-blind. She has some residual vision and can hear loud sounds—and some brain damage. In school she was classified as "mildly retarded". In recounting the family's experience, the only alteration made by the father was to change the names of his three children. His account is reproduced here verbatim.

Sometimes I wonder if my wife even knew the other two kids existed, or even if I existed. The discipline which we both felt was important for the other kids didn't apply to Laura. Janie and Doug had a regular bedtime; they ate all their dinner or no dessert, they had chores as soon as they were old enough to handle them. I tried to tell my wife we should do the same with Laura. I said I didn't think it was right to let any kids run your life. All she would do was give me a line about how she had to make it up to Laura because it was her fault the kid was handicapped. It didn't make sense but there wasn't much use in trying to reason with her, she just got upset; so we couldn't talk about it anymore. Then Laura started at the residential school where they had a special program for the deaf-blind kids. It took more time for my wife to adjust than it did for Laura but we all knew it was the smartest thing
to do. It's hard to explain, but it was like we had two
different families living in the same house -- one during
the week and another come Friday to Sunday. After Laura
was in school for about two months, my wife started to
relax and it was great to see and the kids reveled in it.
During the week we'd take Janie and Doug to a movie;
sometimes we'd go cycling or skating. We never did much
with Laura, because her mother was always afraid it wasn't
safe, or she'd be too bored at a movie. Maybe she was
tight, I don't know. After awhile Janie and Doug got so
they would turn gloomy come Friday morning -- sometimes I
did too; but my wife couldn't understand why.

The people at the School really had a hard time with
Laura when she first started, but they said it wasn't
unusual. From the first conference they kept telling us
to treat her like the other kids, to be "firm", "consis-
tent". My wife really tried but all it took was for
Laura to throw a tantrum and we were right back where we
started. Laura was nine when the worst happened. She had
a tantrum; I lost my temper and spanked her. Okay, I
guess you shouldn't do it when you're mad but, like I said,
I'm human too and I really believed Laura knew she had
the power to turn our lives into purgatory. I still
think it would have been better if my wife had stayed out
of it. She admitted that I didn't hit the kid hard but
it was the first time Laura had been spanked; and because
she was deaf-blind, she didn't understand. Well, to me
that was just so much baloney. I mean, Janie was about
18-months old when her mother spanked her because she kept
pouring milk on the floor if she didn't want to finish it.
Doug was about that age too when I gave him his first
spanking because he kept fooling with the electrical
outlet. Okay, so they had normal vision and hearing; but
I'm darned sure Laura knows the difference between right
and wrong. For whatever its worth, our Minister and
family doctor agreed with me. The truth is that compared
to most of the Rubella kids at her School my daughter is
pretty lucky. She can read large print; she can hear a
little with a hearing aid; and, she is only slightly
retarded. I don't mean I don't wish she was not handi­
capped, but, what the heck, it could be alot worse. Well,
the whole thing was blown way out of limits. My wife told
me I could see a shrink or move out. I said I'd think
about it. She took back the bit about moving out and I
talked to our minister about a shrink, not just on account
of Laura but because I felt scared about all of us.

Doug was having trouble in school. At the beginning
of March his homeroom teacher sent word that if he didn't
shape up he'd have to repeat the whole year. Then Janie
got suspended along with three kids I never heard of
before for smoking. Well, my wife insisted Doug's pro­
blem was that he had a poor teacher. That didn't
make sense because he had at least four teachers— they couldn't all be lousy, let's face it. As for Janie, all her mother would say was that it was just a stage all kids her age went through. In reply to my question about the two girl friends on our street my wife said the only reason they were different is because they weren't caught. It's funny, but it wasn't until this happened that I realized Janie and the two neighbor girls were not friends anymore.

My wife birthday fell on a Wednesday. On Tuesday, I met the two older kids after school to shop for a present. Tuesday came. As Janie, Doug and I drove towards the business district I asked Janie if what her Mom said about the two neighbor girls just being lucky not to get caught was true. The poor kid started to cry:

"Dad, they don't bother with me anymore."

I asked her how come?

"Mom says I can't plan to do anything on the week-end because I have only that time to be a big sister to Laura" and then my usually cool teen-aged daughter feel apart in the back seat and cried like I'd never seen her cry before. I felt helpless and miserable. Then Doug said:

"Dad did you know that Mom forced Janie to quit cheerleaders?"

When I asked why he said:
"Well, almost all games are on Friday night or Saturday. Mom said Janie's place is home." After a pause he went on:

"She can't go rollerskating on Saturday night either. That's why the two girlfriends got mad about. They both have younger kids in the family -- younger than Laura. They take them with them to the skating rink, but Mom won't let Laura go because she says it's too dangerous."

Then Janie said:

"The kids say I was only making excuses because I'm ashamed to bring Laura....I hate her! I know you'll think I'm terrible, Dad, but I can't help it. Between sobs she concluded "Sometimes I don't know if I hate Mom or Laura!"

I'd pulled into a parking place but I didn't move to get out. I told Janie I could understand how she felt and that I would try to help her mother to see it too. She interrupted me:

"But you don't hate Laura and neither does Doug!"

Doug squirmed in his seat. He didn't look at me, but I could see him turn a little pale. When he finally did look my way I could see he was fighting tears. He was looking at me but talking to Janie.

"Mom doesn't bother me about Laura because I'm a boy."

Janie was almost screaming
"She doesn't bother you! I get top grades in school and you won't even do your homework but she doesn't bother you!"
I needed time to think; I knew I had let my kids down -- how had I remained an ignoramus for so long? As I tried to think of something to say, Doug half-turned to his sister and in a small voice said:

"Sis, do you ever feel weird? I mean do you feel funny because you can see and hear? I mean Mom keeps telling us how lucky we are and...well...you know, poor Laura."

Janie came to. She sat up straight and glared at both of us:

"No! Why should I—Why should I have to live like a handicapped person because my sister is handicapped?"

Except to agree that she shouldn't and neither should Doug, I called a halt and suggested a hot chocolate before hitting the stores.

Case Summary

This incident marked a turning point for the family. On the one hand, the mother was genuinely shocked to learn that Doug felt "weird" because he could see and hear. She went all out to reassure her son that there was no reason for him to feel this way. On the other hand, all attempts to effect a change in the mother's
views concerning Janie's responsibility to her handicapped sister met with resistance. The situation was further complicated by the fact that within six months after the crisis came to a head, the husband received a promotion which necessitated a transfer to another State. Albeit the wife was supportive of the move at first, she refused to go on, learning that Laura would have to continue in the same school which meant she would only get home for major holidays and in summer.

With the arrival of summer, the parents endeavored to "patch things up" during the month's vacation which the father spent in his old home. This attempt failed. Eventually Janie asked her paternal grandparents, who lived within driving distance of her father, to take her in. During the second summer after his father moved out, realizing that his mother would not join him, Doug, using his own money and consulting no one, arrived at his father's place of work. He did not return to his mother. Needless to say, the mother was embittered. She felt her husband had rejected Laura and had used the transfer as a means of taking (with his parents' help) the two older children away from her. It is important to note that both parents entered therapy separately for a brief time. The husband said he found it helpful in that he gained new insight; the wife would make no comment. It is my belief that this tragedy might have
been avoided if the entire family had entered therapy. Ironically, the wife agreed, but said it could not be done because there was no way Laura could be an active participant. As the mother saw it, the limitations posed by communication ruled out any possibility of involving Laura in family therapy. However, since it is obvious from the case history that Laura was not a passive observer in the family "dance", there is reason to reject this argument. In the final analysis, Laura's "psychological position" within the family necessitated Laura's involvement, and the involvement in all family members in order for the family "system" could be changed. That Laura was capable of modifying her behavior to accommodate her surroundings is borne out by the adjustment to school life. For example, though she continued to have temper tantrums at home, she ceased having them at school before the end of the first year. At home her mother ministered to her every need; but, at school she not only cared for her own basic needs but came to be relied upon when one of her peers needed assistance.

On the basis of personal experience as a deaf-blind individual as well as my contact with other handicapped individuals and their families during a period that covers almost half a Century, I believe that parents of deaf-blind children, and handicapped children in general,
tend to fall into two categories. That is to say, allowing for the normal and necessary process of grieving on learning their child is handicapped, parents accept the responsibility of raising their child either positively--as a challenge--or negatively--as "bad luck", punishment or "a Cross". To a large extent, the choice will be determined by the maturational level of both parents, their willingness to support each other and the stability of the marriage. Needless to say, the stability of the family and the personality development of the handicapped child (and any siblings) will reflect their choice. In the case history which follows, the material is provided not by the parent but by the deaf-blind child (now an adult).

Celia

Celia's deaf-blindness is attributed to an accident in the delivery room at the time of birth. For eleven years the general consensus was that she was blind and severely brain-damaged. When she was eight years of age, an otologist stated that she was not retarded, but deaf and suggested that she be enrolled either at the Perkins School for the Blind--which has a deaf-blind department--or a school for the deaf. Three years would elapse before either the diagnosis or suggestion were accepted and acted upon. Even before she was born her parents knew domestic discord, due primarily to the fact that her
father was a compulsive gambler. This discord was to have profound effects on Celia's development and, to a lesser extent, on the lives of her siblings. Before quoting Celia however, it should be noted that, as a child, she had some residual vision; and, at the age of twelve, it was discovered that she could benefit from the use of hearing aids. Subsequently, through speech therapy, supplemented by hearing aids, Celia eventually reached the level where she could communicate verbally on a one-to-one basis. Succinctly stated, this means that at the age of 18 Celia was reclassified from deaf-blind to severely hard-of-hearing. She would return to the world of the totally deaf-blind ten years later as the result of a stroke. Celia recalls:

I used fingerspelling while I learned speech, but I couldn't function in a group, like a classroom or in the cafeteria. I felt left out of things at school, but it was even worse at home. It was easier at school because I worked hard, made good grades and gained some self-confidence because I knew I was doing better than most of the blind kids -- there were no other deaf-blind kids doing regular academic work at that time. But home was another thing. I thought Mom and Dad would be pleased but it didn't make any difference. Even now its hard to say it, but I never really felt
Mom loved me. When my only sister came (I had three brothers) Mom tried to have me adopted. In fairness to my mother, I don't really know what my father's role in that incident was. But, even though he had as hard a time as anyone else communication wise, I remember him as a gentle man who took pains to teach me things like how to swim, bounce a ball, and much to my delight, he'd turn the radio on, take my hands in his and try to teach me to dance.

Entering the deaf-blind department was sort of like living in two worlds. At school people encouraged me to take pride in myself—so did my speech therapist. But when I'd make a friend and felt happy Mom would insist that if someone was nice to me it was either because they wanted to take advantage of me (like a boy) or they felt sorry for me. By way of vindication for this statement she said I was her "Cross" in life like my Dad, and, like my Dad would never amount to anything. I was really confused; and, sometimes I'd get so depressed I felt I'd be (as Mom often told me) better off dead.

As strange as it may seem, I wanted to go home on week-ends, but I dreaded it because Friday was Dad's payday and there was usually a fight between my parents. After a while, since the fights were always bad on Friday night, my brothers and sister
came to hold me responsible. The result was that in time when we'd all grow up, I really believed--wrongly as it turned out--that they would come to know and love me as a person. Truthfully, I never actually knew what my siblings thought of me because they didn't really communicate with me. I didn't come to special events in their lives and family vacations I was not included--vacations were planned for a time when I could be sent away to a camp or was in school.

I was devastated by the fights on Friday night, but if I cried Mom would hit me and Dad or my little brother would try to intervene; so, I learned to stay out of her way.....My parents were separated twice before I finished high school. The first time I was about four. The first time relatives and friends offered to take my brothers in but no one would take me. Consequently, I was the only one of the kids to be placed in Dad's custody. But, he had to work. He found lodging with one of his sisters who was married but also worked full-time. So, I was sent to a children's shelter. My father visited me only once, because I cried when it came time for him to leave and had to be pulled away from him. The second time, I was about fifteen. My mother took me on week-ends but my brothers
and sister avoided me like the plague. One reason for this had to do with a rule Mom had: whoever was in the "doghouse" at the end of the week was given the chore of picking me up at school on Friday and taking me back on Sunday. Once home, nobody came near me. I'd sit on my cot or in the livingroom. I'd try to read or study, but I felt miserable. People at school began to notice the change--I did my work, but I was withdrawn and I cried a lot. It's funny. I didn't even know the word "psychiatrist" let alone what they did; but suddenly the school was sending me to one. It took a while, but I came to trust him. And, as he learned more from me, he asked to see my mother. Mom agreed finally to see him and although I sat in the outer office, she did take me with her. Well, I never saw him again, although he and the school's social worker tried to arrange it. When my mother and I arrived home after her interview with the psychiatrist, I got the worst strapping of my life. I was a "liar" and an "ingrate".

I've often wondered what would have become of me if I hadn't gone to college. Don't get me wrong: it was no joy ride, but as the saying goes, everything has a price. I didn't expect to be accepted. All I wanted to do was get a degree so I would be
in a better position to do something useful with my life. To be truthful, there was another reason: I wanted to prove that I could amount to something; I wanted my family to love me. As time went on I made friends among my college classmates and some professors too. It's hard to explain...I wanted to be close to my family but in order to learn to live with myself found it necessary to stay away from home as much as possible. I wish I could tell someone even now how much I envied kids who had close family ties. What I'm saying is that I needed to believe in me as a person but that wasn't possible if I saw myself as Mom's "Cross". I didn't want to believe that people felt sorry for me. Oh sure, some do even now, but not all.

I lost what little sight I had when I was fifteen. I got hit with a swing and the retina on my good eye became detached. In my senior year of high school I finished speech therapy and training to use hearing aids. I was then re-classified from deaf-blind to blind and severely hard-of-hearing. I knew I was lucky, and I think I tried to make the most of it. Maybe I should have paid more attention to the doctors who warned me that, because "only a thread" bound me to the world of the hearing; and if subject to a lot of nervous tension that thread
would break. Ironically, when it did break, returning me to the world of the deaf-blind, it wasn't nervous tension but a stroke that caused it. Before that happened I had finished college, held a good job; married; and became a parent. There's another thing. I'd always prized my independence which was a good thing because it helped me to accept and adjust to being totally deaf-blind. I don't mean I found it easy, or that I liked it, but it wasn't anything I could change.

Being a parent myself has helped me to understand and appreciate my parents. When I was little they didn't really know the extent of my handicap. My mother was busy taking care of us and keeping house. It is true that during times when she and Dad were fighting she could be pretty abusive; but, without sight or hearing I had no way of knowing that I was not the real cause of the problem. During tranquil periods she left me alone, except she did teach me to dress myself and stuff like that. On the other hand, my father was really good to me when I was a little kid. He taught me to swim, to bounce a ball, to use a swing. Maybe I'm wrong, but even though he too changed when all hope of a "cure" or "miracle" was lost, I never felt that he didn't love me. That wasn't true of Mom, especially
after my sister was born. I guess no one could blame her, my sister is "normal", someone to be proud of, whereas I evoked feelings of shame.... Look my mother is not a minority of one: there are lots of people who feel the same way. All I know is that it is their problem. I didn't ask to be deaf-blind, but I have to live with it.

Case Summary

It is interesting to note that Celia found it necessary to rely on "significant others" outside her family constellation and an environment other than the home before she could achieve a positive sense of significance. From early childhood through her teens she struggled with the conflict between her self-concept -- a desire to believe herself as a person of worth and her self-ideal--that of the handicapped person of little worth except as an object of pity. To further complicate matters, she was receiving contradictory signals from home and school as to what the world expected of her. It is not surprising that she was deeply troubled by the time she reached her junior year of high school: nor is it surprising that her mother, given the circumstances of her self-appointed martyrdom, forbid any further session with the therapist. That is to say, the therapist tried to get the mother to consider
alternatives to her daughter as a "Cross". Fortunately, at the time, therapy sessions were terminated, Celia had been seeing the therapist for the better part of the school year. What made this experience of special value to her was the fact that for the first time in her life she had someone with the patience and communication skill who encouraged her to express her feelings. The therapist was himself hearing impaired and devoted much of his practice to deaf and hearing impaired individuals.

Jackie

Jackie's parents were both raised on farms. They had only one child. All three were living contented happy lives when Jackie became ill. Jackie related her experience as follows:

From the beginning, I had normal vision and hearing and no physical defects other than a lot of freckles on the nose. I played with other children—when they were available—went to movies, rode horseback, climbed trees, rode a small bicycle and went to school.

In November of 1935, when I was in second grade and only two months away from my seventh birthday, I was suddenly struck down with an attack of meningitis...Coming out of the coma, I slowly came to realize that I had completely lost both sight and
hearing. Nothing remained of either.

This was no great shock to me nor much of an upset for that matter. Being a child I was blissfully unaware of how hopeless the situation was. My mother, who was a registered nurse, had often attended sick people in their homes where I would visit her, if the place happened to be near enough for me to reach from our house. On the basis of these visits I observed that people could be sick and suffer effects after recovering but they always grew completely well in time. I supposed my condition was the same. I might be deaf and blind for a time, but I was sure I would regain both in time and life would be just as before.

For the next year and nine months I spent my time at home with my parents, playing with other children when they visited me and with my cats and dogs. Communication was limited to signs we developed by ourselves and to questions that could be answered by "yes" or "no".

My parents' reaction to the discovery that they had a handicapped child was the usual — what could be expected. Mother cried at night and Dad was very unhappy. They didn't drag out grief or pain any further than was normal. After the first few weeks, they settled down to accept what had been handed
them. They continued to treat me the same as they had before I lost my sight and hearing. They did not coddle me nor overprotect me. I could and did go for walks with other children; I could and did wander alone outside the house or in the backyard. Other than the fact that I was not going to school and there was a communication barrier, my life was not so very different from what it had been before.

In 1937, when I entered a State residential school for the deaf and blind, the same campus but separate programs for each group, there was only one other student who was both deaf and blind. The School Board did not like the idea of my attending school, partly, I think, because the teachers were not accustomed or trained to work with deaf-blind students. Then too, the other girl was due to leave in one year which would mean I would be the sole deaf-blind student in the whole school for years to come. They said I should go to Perkins where there were more deaf-blind students, but the School Superintendent said "No, she should attend this school."

When I started school in September, a special speech therapist had been provided for me. She had been trained to work with sighted deaf children only,
but managed to improvise. She taught me Tadoma and worked to improve my speech which had started to deteriorate. After I learned to understand anyone verbally using the Tadoma method, and after learning to read and write, communication ceased to be a barrier. If I missed out on some word or phrase, people could just print it on my palm. The following year I was taught sign language and finger spelling for use at meetings or with groups. For most of my handicapped life however, I have circulated among "normal" people or hearing blind people who do not know sign or fingerspelling. I am an expert at fingerspelling, but since I have had such little opportunity to use it, I promptly forget what signs I learn. I prefer Tadoma in ordinary conversation unless the other person is too difficult to understand. People who are hard for me to use Tadoma with are those who slur their speech, mumble or talk at a rapid-fire pace. Another advantage Tadoma-users enjoy is the ability, to some extent, to read facial expression, which does help in interpersonal relations.

Although I missed my sight much more than hearing, I would say that deafness is much harder to live with than blindness. I do not always understand what people say to me—either in
fingerspelling or Tadoma— and they get very impatient and angry. Also, it's a nuisance not to be able to use a phone at any time or place; and another nuisance is to be constantly obliged to tell people I am deaf, because I can speak. Yet again, there is the unending problem of finding interpreters when ever I go to a meeting or conference.

At the time I became deaf-blind, neither my parents nor myself received any counseling. In fact, I don't even think they were available at that time. The only unpleasantness I remember during my years at school was a mean-tempered teacher. There was no pleasing her, everything I did was wrong. It had nothing to do with my being deaf-blind though, because she was the same way to everyone.

Case Summary

It was Jackie's good fortune that her parents were able to provide her with a calm and supportive environment during her adjustment to deaf-blindness. Encouraged to move freely about her surroundings nurtured her sense of independence which, to any deaf-blind person, is a valuable asset. The fact too that her school environment was in harmony with her home environment
served to minimize the feeling of inferiority -- "I am deaf-blind; normal people can see and hear" -- to which many deaf-blind children are prone.

The reader should not be surprised to learn that Jackie, after completing high school went on to receive a college degree. She has become one of the most successful deaf-blind individuals in this country in her position as a consultant for a State Department of Education.

It is important to note that Jackie was correct in stating that counseling per se was not available to newly deaf-blind children and their families at that time. Albeit rehabilitation counseling was available in a majority of States, it did not apply to children or even adults with "severe or catastrophic disabilities" until 1965 (Oberman, 1965, p. 179).

Dependence Versus Independence

As the reader will no doubt concede, Jackie's account is a tribute to the parents and families who find the strength and the courage to accept deaf-blind children, sibling or spouse positively. In most instances where this state of affairs is absent, there is a prevailing tendency, as stated earlier, to become overprotective. Implicitly, there are two aspects of "overprotectiveness" which need elucidation 1) the underlying motive of the perpetrator(s) and 2) the reaction of the deaf-blind
individual.

The three most recurrent motives are (a) the lack of the necessary patience either to assist the deafblind person in acquiring whatever skills are needed or to allow them the time to master the needed skills on their own; (b) the need to feel important; (c) the need to assuage feelings of guilt by encouraging dependence. Whatever the motive may be, it is an established fact that the overprotection is detrimental to the deaf-blind person's need for self-actualization.

Generally speaking, the reaction of the deaf-blind person who is over-protected is either submission, resentment or challenge. Unfortunately, whatever the choice, there is a price to be paid. Through SUBMISSION, FOR EXAMPLE, THE DEAF-BLIND PERSON RELINQUISHES A SEGMENT OF HUMAN EXISTENCE WHICH PROMOTES SATISFACTION AND SELF-FULFILLMENT. Since resentment is a negative emotion, it causes mental anguish and feelings of inferiority. By way of illustration, the following quote is an entry from Helen Keller's journal dated June 30th, 1898, when she was eighteen-years old.

..... Nothing to report, except that I again lost my temper, and it was so silly. I said I'd like to learn to keep house. "Don't talk such nonsense," the family said. "You will never like it. You don't do anything neatly. You leave your bed looking as if
Buff (the puppy) had dug into it. You leave your windows open when a rainstorm is coming. You'd send all the dishes to limbo if you tried to wash them." I was hurt and said "Why do you keep telling me those things all the time?" That wasn't true or fair, they were only laughing at me. (Lash, p.244)

To challenge the perpetrators of over-protection, though the most desirable reaction, usually meets with resistance. The deaf-blind person is left with feelings of uncertainty; subject to humiliation; and, to the regret of all though seldom aware of it, alienated. For example, Celia (see page 34) in her efforts to eliminate over-protection, and assert himself, found it necessary in the long run to cut her ties with her family in order to achieve a semblance of independence. In the process she was to know a sense of aloneness which was not related to basic methods of communication. She writes:

I still feel sad when I think of what Mom could have taught me if she had even tried. I had to rely on myself, kids at school and, later, friends to teach me even the simplest things like boiling water. Oh sure, I tried to do things at home but soon gave it over because it brought nothing but trouble and humiliation. What made it hurt even more was that my helplessness was a family joke: "If the poorhouse can't keep one lady its just too
bad: they would say laughing.

Coping

On numerous occasions different people have asked me what enables an individual to cope with the limitations and varying degrees of isolation imposed by the loss of sight and hearing. Succinctly stated, psychological survival necessitates accepting the situation and attempting to make the best of it. In the biographical sketch which Jackie (see page 42) submitted to me, she speaks of the need deaf-blind people to have a "philosophy to carry them along through the knocks and bumps of life, and to use as guidance in their behavior and activities."

Hellen Keller too had something to say on the subject. Among the excerpts from her writings published in the OPEN DOOR is the following:

No one knows - no one can know-- the bitter denials of limitation better than I do. It is not true that I am not sad or rebellious; but long ago I determined not to complain.....But to get the better of fate....one must work and the solace of friendship and an unwavering faith in God's plan for good. (Keller, 1957).

Miss Keller knew deaf-blindness from infancy; Jackie from age seven. Richard Kinney became blind at seven and deaf-blind some 15 years later. Interestingly enough, statistics reveal that 80 percent of the deaf-
blind minority go through a time sequence similar to that of Kinney. He went on to become an internationally known educator and lecturer. Here is what he had to say:

Each time I am buffeted or deflected out of a sense of hidden strengths and purpose, buffeted by circumstances of adversity, I come back to this theme. A compass needle can be deflected, but something within it turns it north again. (Crist, p. 21).

Conclusion

The primary objectives of this chapter have been (1) to enable the student of psychotherapy to realize that, when a deaf-blind person, or the family with a deaf-blind member becomes a troubled one, the presence of the double-handicap, more often than not, is only the surface cause. For example, the wife who wants a career only to find she is pregnant with a child she does not want is apt to experience feelings of guilt. Her attempts to deal with these feelings result in either the rejection of the child or over-compensation. In either instance, there is likely to be an adverse effect on the emotional and personality development of the child. To use a classic illustration comparable to Laura's (see page 25), where the child was born "normal", I refer the reader to DIBS (Axline, pp. 81-92; 1976). Interestingly enough, Dibs was referred for therapy.
Such an alternative would not have been available in Laura's case but the need for help by the family was even greater—if that is possible.

Albeit Celia (see page 34) was sent for therapy; but she was more handicapped by her troubled family than by her disability. Like Claudia in FAMILY CRUCIBLE, individual therapy was not the answer, was in need of help. Like Claudia, Celia was in the middle of a triangle between her parents; she was the family "scapegoat" (Napier and Whittaker; 1978, pp. 44-58).

(2) Obviously, the "psychological position" of the handicapped child is of crucial importance.

(3) The experience of Jackie and her parents (see page 42), appears to give substance to the importance of the maturational level of the parents and marriage stability on the personality development of the deaf-blind child.

(4) The need for self-actualization is as inherent in a deaf-blind individual as in a "normal" individual. Similarly, there must be congruence between the self-concept, self-ideal and "not-self"—the world at large. By the very nature of the limitations imposed by the elimination of the feedback which a "normal" child assimilates from the environment, the deaf-blind child must rely more heavily on the significant others in her/his life and on their own inner resources.
CHAPTER III

OUR "SENSES" AND OTHER ASSETS

Though it is impossible to minimize the salient problems confronting the individual who knows the deprivation of the primary senses, it is possible to exaggerate them. From the psychological perspective, such exaggeration is rooted in fear—"There but for the grace of God go I";—and ignorance as to the ways and means by which the deaf-blind person can achieve a fair measure of independence or freedom. The plight of the person who is deaf-blind is, by virtue of the limitations imposed, comparable to that of a man in chains. However as Wheelis has observed:

.....a man in chains need not be a slave. If he has pride and self-respect he is a freeman, though a prisoner and a constant threat to his jailors...

(Wheelis, 1973, p. 75)

Sight and hearing are known as the "distance" senses. For example, as you make your way down the street to the Post Office, someone calls to you. From a distance, the words may be audible; you may even recognize the voice. However, it requires the normal eye to tell you from whence the sound came. At a glance you can identify the speaker as friend or stranger.
Interestingly enough, many people who have been blind since birth or for a long period of time, state that the ears can be trained to the point of enabling an individual to localize sounds in such situations. As the late Mrs. Richard Kinney, congenitally blind once commented:

It is not true that the blind hear better. It is just true that they train themselves to listen more carefully. A lot of people are amazed that a blind person does not run into a solid object, but they could do the same thing, without seeing, if they would train their ears to the sound of footsteps, to hear the bounceback of objects (Crist, 1974, p. 212).

Listening for the "bounceback of objects" is a phenomenon known as echo perception.

Attitudinally, for many of its victims, blindness is considered more of a "nuisance" than a "disability". This view is stated clearly in an address delivered in 1957, by the late Dr. Jacobus tenBroek, blind university professor and guiding spirit in the organized blind movement. His statement reads:

Let me be very clear about this. I have no wish to minimize the character and extent of blindness as a disability. It is for all of us a constant nuisance and a serious inconvenience. To overcome it requires effort and patience and
initiative and guts. It is not compensated for, despite the fairytales to the contrary, by the spontaneous emergence of a miraculous "sixth sense" or any other magical powers. It means nothing more or less than the loss of one of the (primary) senses and a corresponding greater reliance upon (those) that remain—as well as upon the brain, the heart, and the spirit (tenBroek, 1957, p. 7).

This view is held by many members of the deaf-blind minority, especially those who are congenitally blind or who became blind before adulthood.

In August of 1982, this writer conducted a survey at a national convention for deaf-blind individuals. When the delegates were asked which of the absent senses they felt to be the most difficult to live without, the majority of the respondents chose hearing. It is interesting to note those who selected "sight" as their choice, with a few exceptions, were the congenitally deaf and adventitiously blind. With regard to the majority choice, the following quotation from a man who possessed both senses for a time is enlightening:

The trouble with most people is that they forget everything they saw and heard yesterday, thinking always about how much more there is to see and hear tomorrow. They pass right by the beauties of today (Crist, 1974, p. 17).
Over a period of years I have, as a deaf-blind person, gained an awareness of at least one factor which contributes to the valuation to blindness as a "nuisance". Succinctly stated, I refer to the necessities of conforming to certain societal norms. For example, during public speaking engagements, one recurring question is "How do you know what color garment you are wearing? A blind or deaf-blind person has three alternatives: (1) Enlist the assistance of a family member, or some other person with vision. Albeit this is the easiest alternative, it is undesirable from a psychological point of view, because it nurtures dependence. (2) A blind or deaf-blind person can obtain, free of charge, from the Aids and Appliance Division of the American Foundation for the Blind (15 West Sixteenth St. New York, N.Y.) packets of metal tags. Each tag is marked in Braille with letters designating a particular color. For instance, "wt" for white, "br" for brown, "bk" for black, etc. These letters can be sewn on the inside of a garment thus enabling the user to identify its color. The tags are sturdy enough to go into the washer and dryer; but, the wise user reinforces them occasionally. (3) Relying on memory, and careful selection with regard to fabric texture and style. By way of illustration, two skirts may be corduroy and identical in style,
except the one has loops for a belt; two blouses may be of the same style, but made of different material. Detractors of this method say that it is not as versatile for men as for women; and its application is limited to people with small wardrobes!

Of additional interest, psychologically, is the tendency on the part of many to display bias with regard to the societal norms governing personal appearance. Hypothetically, consider the occasion of a business luncheon. Diners would be more likely to take notice of a blind or deaf-blind man wearing a poorly coordinated suit and tie than a "normal" man similarly attired.

Needless to say, the human condition of deaf-blindness is not one which an individual would willingly choose. However, in lieu of the tendency in our society to extol the virtues of "eye contact" and "body language" as the prima facie in enhancing human relations--both personal and professional--there is a pause for reflection. That is to say, since these "virtues" are beyond the reach of many deaf-blind--especially those who are congenitally blind--does it follow that meaningful, close relationships cannot be experienced? Or, through the utilization of the remaining senses, and powers of perception, is it possible for a sensitive, intelligent deaf-blind person to relate at a more desirable level?

In as much as the life of Helen Keller alone is living
testimony to the ability of a deaf-blind person to experience intimate relationships with other human beings, we know that other avenues of human interaction are available. Given the circumstances of the absence of visual and auditory stimuli—e.g. facial expression, gestures, tone of voice, etc.—the reader is invited to explore the hypothesis that, in the realm of interpersonal relationships, the deaf-blind person experienced more of the "inner" as opposed to "visable" person. For this purpose, the following is an experience of a totally deaf-blind friend.

About six months after I started my new job, two friends from my hometown came for a visit. I had written them about my supervisor and was really anxious to have them meet her. The first thing I liked about her is that she's a first-rate fingerspeller. Sometimes when things were slow, we'd sit and talk about everything under the sun. To me she came across as real interesting, funny and friendly. One thing though, if she was in a bad mood I sure kept out of her way.

When I met my friends after work, I got a big surprise. They said as far as they were concerned, my supervisor was a "cold fish"! Over the next week, I asked almost everyone that worked at the place what their opinion was. In all of fifteen people,
two disagreed with my friends. They said she hardly ever smiled. They were turned off by her temper and the way she talked down to people. That was awhile ago and as you know, she's one of my best friends; but, most of the other folks hate her. The weird thing is that the people who like her best are like me: they can't see or hear.

In the final analysis, the reader probably knows of --or is--a person whose "exterior" is a mask which protects a sensitive, insecure and more often than not, lonely "interior".

One elucidating factor in the experience cited above which is of particular significance concerns the use of tactile fingerspelling (the one-hand manual alphabet) as a communication modality. Having used it for more than 35 years, I have found that it often encourages intimacy in that it is private, hence, personalizing. Concomitantly, it is of positive value in minimizing, if not actually eliminating, the phenomenon known as "mixed signals". There is a report of a psychological study (Napier, Whittaker, 1978, pp. 44-45) which poignantly discusses both the nature and adverse effects of this phenomenon. A summary of the relevant aspects of this study follows.

In the early 1950's the prevailing view was that schizophrenics responded to their own internally warped
view of the world and were subsequently out of contact with reality. However, prompted by the fact schizophrenic patients became extremely upset following visits from their mother, a group of researchers began making observations in an effort to disclose the reason. What they did was to observe the interaction between patient and mother during hospital visits. It was discovered that, far from being out of contact, patients became involved in an intricate and disturbing pattern of communication with the mothers. It appeared that this communication was taking place on two levels, verbal and nonverbal, and the messages being received were in conflict.

To illustrate: when mother arrived for a visit, the patient, obviously happy to see her, greeted her with a smile and a hug. On the verbal level, mother responded warmly enough; but when accepting the hug she stiffened slightly. Sensing the nonverbal rejection, the patient backed away. Naturally mother tried to deny the conflicting message she was sending, forcing the patient into a situation which the researchers called a "double bind"—trapped between two conflicting messages. In order to respond to the verbal warmth, the non-verbal message would have to be ignored. But when the patient responded to the nonverbal message, not only did mother deny its validity, they couldn't talk about their ambivalence in their relationship. For the patient, the
end result was conflict.

In a similar situation, a blind person's initial response would be to the warm greeting--the auditory message;--a deaf person's response would be to the smile--visual message;--a deaf-blind person would be aware of neither. Like the schizophrenic however, the vast majority would be aware of the nonverbal message. Implicitly, albeit the absence of both senses is limiting, being restricted to one level can be an advantage. Needless to say, much will depend on the deaf-blind individual's insight or level of perception. Obviously, accurate perception necessitates developing innate mental ability to the fullest. In this respect, it is interesting to note that psychologist William James once observed that human beings only make use of ten percent of their brain.

The Secondary Senses

The Sense of Smell

From the standpoint of safety our sense of smell, known as the olfactory sense, can alert us to fire, burning or spoiled food. At the practical level, the sense of smell enables us to differentiate between the salt and pepper shakers, tubes of toothpaste and shoe polish; the laundromat from the beauty parlor. The sense of smell then is a tremendous asset to the deaf-blind per-
son. Also, the deaf-blind person derives a great deal of pleasure from the sense of smell: burning leaves, a flower garden; the smell of brewing coffee or freshly baked bread. However, the widely held belief that blind or deaf-blind persons are endowed with a keener sense of smell is erroneous.

Smell consists of vapors in the air which produce chemical reactions in the special olfactory cells. Since the most sensitive of these are found high up in the nose, best results are achieved by sniffing the air up into the nose. Psychologists claim that there are basically six primary odors from which all other odors are derived by blending. The sense of smell then can be cultivated.

The Sense of Taste

Taste is a contact sense, in that it must be in contact with the "taste buds" in our mouths before we are aware of flavor. Whereas smell involves vapors in the air, food must come in contact with liquid before we can taste it. To illustrate, the fact that your mouth is dry when you have a head cold is what causes the impression that anything you put in your mouth seems tasteless. In other words, food must be moistened by saliva or some other liquid before we can taste it.

Different parts of the tongue are sensitive to
different flavors. Albeit salty food can be tasted by any part of the tongue, sweets are best savored on the tip of the tongue. The sides of the tongue react best to sour food, while the back of the tongue is most responsive to bitter tasting food. For this reason we can influence the taste of food by holding it (or rolling it) in a designated area of the tongue. Of equal importance, our sense of taste is affected by smoothness, chewiness, cold or warmth. Realizing that the senses of smell and taste are interrelated, good cooks insist on serving food on heated platters because it enhances the aroma.

The Sense of Touch

For the average person, the sense of touch is equated with the hand. In point of fact, "touch is really a cluster of senses including pressure, warmth, cold, and pain. "Touch" involves the skin of our entire body, and keeps us in contact with reality--the bed we sleep on; the floor we walk on; the chair we sit on. Also, blends of the clusters mentioned above convey other impressions, such as hardness and softness, smoothness and roughness, wetness and dryness, stickiness, itchiness and vibrations. Sensitivity of the skin varies in different parts of the body, the tip of the tongue being the most sensitive. Consequently, the tendency infants
have of putting everything to their mouth is usually prompted by a desire to explore it with their tongue rather than hunger. Fortunately for those of us who use braille, the fingertips are the next most sensitive area of the body's skin surface. And, for the deaf and deaf-blind, the human hand, which is capable of arranging its four fingers and thumb into an estimated three hundred million potentially useful positions, is of inestimable value as a tool of communication (Kinney, 1972, p. 3). As Helen Keller once commented:

My hand is to me what your hearing and your sight together are to you....All my comings and goings turn on the hand as a pivot. It is the hand that finds me to the world of men and women. The hand is my feeler with which I reach through isolation and darkness and seize every pleasure, every activity that my fingers encounter (Keller, 1905, p. 455).

**Psychological Implications of "Touch"**

As we go about the business of daily living, few of us will deny the pleasure derived from a warm handshake from a hug or embrace from a friend or loved one. We know also, that medical experts extol the virtues of "tender loving care" during illness. Yet, it is a sad fact, that our society tends to discourage physical contact.
The adverse effect of this was made clear to me recently by the experience of a young friend who is a resident aide at a residence for college students. One evening, my friend stopped me to ask if I knew of his plan to initiate a "hugging club". When asked for the details he reminded me that I had often expressed concern for the many lonely young people at the residence. It was his belief that a "hugging club" might be a means of reaching some of them. The meeting was duly held. A summary of his report reads as follows:

There was a good turnout: about 50, mostly girls. Most of the kids just watched from the sidelines. When an effort was made to get them involved they were embarassed especially the "guys". Let's face it, it's o.k. for a girl to hug another girl, but guys just don't do that! The next time we meet, we're getting a barrel of beer. Maybe after a couple of beers the guys won't feel so self-conscious.

...It's funny but almost everyone I know either took or wants to take the course in human sexuality. It's a good course but I wonder if that's really what we need.

It is interesting to note that a baby reaches out instinctively to touch a person or object within its range. More often than not, this tendency is curbed--and not always for reasons of safety--by the repeated
admonition "Don't touch!". The most salient aspects of this "curbing " lies in the message it conveys: "to touch is wrong (or bad)". Logically, such a message is not conducive of enhancing the developing child's desire for tactile contact. It follows that unless the child both receives and is encouraged to display affection, the resulting inhibitions will be carried on into adulthood.

To some extent, the sense of sight can compensate for the loss of tactile freedom. The sense of hearing, especially since it facilitates language development, provides an additional compensation in enabling the child to ask questions about what he/she sees, in an effort to satisfy innate curiosity:

"What makes a clock tick?"

"How come birds can fly?"

Deprived of either or both primary sense, the human hand becomes the instrument for exploration and communication. Functionally, it would be difficult to inumerate the many ways in which people use their hand during the course of any given day. It is necessary, however, to differentiate between the hand's practical function—e.g. to write, eat, shave; and expressive function—e.g. patting a friend on the back, stroking the hand of a loved one. In either case, the primary objective is need, satisfaction or gratification, the differential
factor usually relating to whether this is intrapersonal or interpersonal. For example, whether writing a letter or signing (meaning sign language) the need is to communicate. But, the first is carried out alone, thus indirect, while the second involves the direct participation of another. However, with regard to the deaf-blind minority, a crucial factor, though missing in our first set of examples, is clearly discernable in the second set of examples. Explicitly, the factor to which I refer is tactile contact. Succinctly stated, the individual who is inhibited in the area of tactile contact will find it difficult to relate to a deaf-blind person. This being the case, when the individual is deaf and becomes blind, the task of dealing with such inhibitions is of major significance in their adjustment.

Enlightenment on this subject is provided in an article in which the author, who was deaf at the time, describes an incident occurring at the onset of blindness. As a senior at Gallaudet College for the Deaf, the author of the article was involved in an accident which resulted in a head injury that necessitated major surgery. After returning to her parents' home to recuperate, she suddenly and unexpectedly lost almost all her vision. She writes:

...Then, one late afternoon, as I was walking to the living room to see what the rest of the family was doing, everything went suddenly dark. Alarmed, I ran to the
nearest door flicking the light switch to see if the lights were working. I thought that the light bulbs had burned out, and I tried every switch I could find several times. But I never saw any light.

Then I panicked and walked to the living room, calling out, "Mother! Father! Where are you? I can't see you!" Everyone came up to me and touched me, but because I was blind without realizing it, I was frightened at being touched (Smithdas, 1982, p. 72).

In the course of time, the intelligent deaf-blind individual learns that the hand can serve them in many ways. Like the surgeon, they know that it can be trained, through practice, to incredible delicacy and sureness. Through the sense of touch, they can derive as much pleasure from the flowers in a garden as a seeing person does through viewing them.

Given the added factor of perception, the touch of a hand is often a clue to the personality of a stranger. For example, the firm unhurried handshake conveys an impression of friendliness and warmth. However, if the person drops the hand after a mere perfunctory shake, the impression conveyed is indicative of what psychologists call the "withdrawal" reaction--the opposite being the "approach" reaction. By the handshake, a deaf-blind person can instantly deduce something of the stranger's height by the angle of the arm from the elbow--the slant will be down for
a shorter person and up for a taller one.

It is imperative to note that we who are deaf-blind must be constantly on guard against reading too much into clues, because there are probabilities covering a wide range of possibilities. That is to say, a person may display the "withdrawal" reaction on being introduced to a deaf-blind person for the first time simply out of shyness; or, awkwardness in a novel and seemingly complex experience. It is equally important to note that, deaf-blind individuals are often judged as being inapproachable because the nondisabled person fails to realize the need to make tactile contact. From personal observation I have found that children seem to realize this need instinctively --my son and his toddler friends never had to be told nor did my sighted students.

The Kinesthetic Sense

From this sense, we derive awareness of what our muscles are doing--our movements pulling, pushing. For example, you may use your eyes to cut the meat on your plate but it is your memory and muscles which enable you to bring the food from your plate to your mouth. Similarly by utilizing memory and muscle a totally deaf-blind person can rise from an easy-chair in the living room and walk confidently to any other room in the house. Of course, we are dealing also with our equilibrium--or sense of balance--in that it alerts us to our position and direction
of motion in space.

Our sense of balance is controlled by a delicate mechanism within the inner ear. Consequently, when the cause of deafness is related to damage to this mechanism, the victim experiences difficulty keeping their balance. In some instances however, poor balance can be traced to the fact that the deaf-blind individual does not exercise or have the opportunity to take regular walks. Suffice it to say, walking takes practice—ask anyone who has ever had a broken leg or watched a toddler trying to walk a straight line.

Other Assets

In addition to utilizing the secondary senses, the deaf-blind individual needs to develop their mental abilities to the fullest. It shouldn't be surprising that, unless brain damage is in evidence since birth the greatest terror which a deaf-blind person can experience is that of losing their mind or any of its most sanguine elements—e.g. memory, ability to reason.

Geraldine Lawhorn is a deaf-blind instructor with the Hadley School for the Blind, which is the only correspondence school in the world which caters to the needs of visually impaired and deaf-blind students. Jerrie writes:

I'm working in my teaching to help my students see--
yes, that's the word;--that our minds can dominate, that materially we express only what our minds are doing. If we could improve ourselves mentally to our potentials, if we fully realized our mental might, there wouldn't be any time left to think and fret about the body (Crist, 1974, p. 209).

Implicitly, what you notice about the world depends not only on what you perceive with your senses; but also on your imagination. But, what you can imagine or experience also depends on what concepts you have. As the philosopher, Kant, observed: Intuitions without concepts are empty.

Jerrie Lawhorn is in a position to know the explicit meaning of her statement, for in addition to the disabilities of being deaf and blind she has had to cope with a third social handicap--being black. She is also aware of the fact that whether disabled or nondisabled, a sense of humor--the ability to see the lighter side of life--is a valuable asset. She is familiar with the comment of a former colleague Richard Kinney:

...to laugh with others at life's frolicsome foibles or hilarious incongruities--ah, that's art! That's Psychotherapy! (Crist, 1974, p. 198).
Conclusion

To a great extent, the degree of freedom--hence, level of existence--achieved by a deaf-blind person depends on how well they utilize their secondary senses, perceptive skills and innate mental ability. Albeit communication is the determinant which enables deaf-blind individuals to avoid isolation from people, utilization of the remaining senses can reduce some of the complications inherent in deaf-blindness and open new avenues of pleasure and fulfillment. As Robert Smithdas, Director of Community Education at the Helen Keller National Center For Deaf-Blind Youths and Adults, who lost both sight and hearing before he reached his teens has stated:

When these senses (sight and hearing) are lost, or severely limited, the individual is drastically limited to a very small area of concepts, most of which must come to him through his secondary senses or through indirect information supplied by others. The world literally shrinks; it is only as large as he can reach with his fingertips or by using his severely limited sight and (or) hearing.

These severe limitations of sight and hearing, or their complete absence results in isolation and loneliness (Smithdas, 1975, p. 2).

From the psychological perspective, ability to and
opportunity for communication and the factors mentioned above will, in the final analysis, determine whether the individual is "disabled"--i.e. has a physical, mental, or emotional deprivation--or is "handicapped"--i.e., a victim of the societal consequences, such as discrimination, stereotypes, of possessing such a deprivation. That is to say, there are disabilities which carry little or no handicap such as the undersized jockey, the oversized basketball player; and there are handicaps which are void of disability such as the black skin of the American Negro or the religious affiliation of Jews in Nazi Germany. Simply stated, "It is society which creates and imposes the handicap... for it consists of misconceptions of the sighted (hearing) about the nature of the disability" (tenBroek, 1955, p.4).
Chapter IV

INTERPERSONAL STRESS

In the field of psychology during the past two decades, considerable attention has been given to stress as a prevalent factor in contemporary society. However, a review of the literature indicates that the primary emphasis in studies has been on exposure to physical stressors. As a result, insight into the process of interpersonal stress remains elusive. Interestingly, a review of the existing literature reveals that, when studies have been undertaken using samples of disabled minorities, scant effort has been made to include deaf persons in the sample. Insofar as I have been able to determine, deaf-blind persons have been left out completely. Since, as has been mentioned earlier in this text, "isolation" from people is a fact of life for many who are deaf-blind, this omission seems unfortunate. In order to avoid such "isolation" it is essential for deaf-blind individuals to relate well to others. For this reason it is necessary for counselors to a) understand the underlying factors which contribute to interpersonal stress as experienced by the deaf-blind (and other disabled minorities); and b) to explore and implement measures which will enable them to deal constructively with such stress.
Cause and Effect

Setting the Tone

To facilitate the requirement listed under a) above, it is necessary to a) acknowledge the fact that, if presented with a choice, most deaf-blind individuals would opt for integration as opposed to isolation; b) to shun as simplistic the fallacy that "aggression" and "withdrawal" are the sole reactions to deaf-blindness--or any other disability. For example, consider the view contained in the following quotation:

There is a matter-of-fact attitude, taking the handicap (disability) as it is, (like) poverty, hunger, bad luck and neglect, making no fun of the handicap (disability), yet not stressing it by vainly and painfully disregarding the infirmity (von Hentig, 1974, p. 27).

Many students of psychology are aware of the fact that Alfred Adler is credited with the theory of "organ inferiority." However, when taken in totem, I believe the following quotation indicates that Adler's view of the effects of disability were positive and realistic,

"...By courage and training, disabilities may be so compensated that they even become great abilities. When correctly encountered a disability becomes a stimulus that impels toward a higher achievement" (Adler, 1930, p. 44).
Prejudice and Discrimination

Albeit all disabled minorities tend to be victims of prejudice and discrimination, the plight of the deaf-blind is compounded by the awesomeness of their double deprivation. Their susceptibility to stress in interpersonal relationships is, to a large extent, nurtured by the fact that the number of individuals--both professional and non-professional--who possess the necessary communication skills to relate to them is comparatively small. In any case, the primary difficulty confronting the deaf-blind individual, as stated by Erving Goffman (1963) is the need to differentiate between social identity--the character attributed to deaf-blind persons by others in their environment on the basis of cultural and individual stereotypes--and the deaf-blind person's personal identity--his "self-ideal." According to Goffman, the latter consists of the individual's "subjective sense of his own identity and the continuity and character that an individual comes to obtain as a result of his various social experiences" (Goffman, 1963, p. 105). Each type of identity interacts in a dialectical fashion. Each contributes to the evolution of the other. When this interaction destabilizes an individual's sense of self, the result is ambivalence. Implicitly, in order to deal with this ambivalence, the individual either alters his personal identity to conform to how others see him, e.g. viewed as helpless, though he believes he is capable of at least a
semblance of independence, he conforms to the point of either partial or complete dependence. Or, he may strive to maintain his own personal identity and endeavor to change other people's perception of him. In other words, on the basis of their interpersonal identity, they will learn either to conform to existing societal stereotypes or to take the initiative and assertively challenge such stereotypes in a manner which is more congruent to their self-perceptions. It is interesting to note that research supports the latter alternative as being the only valid means of affecting change (Stensrud and Stensrud, 1981).

The complexity of the choice confronting the deaf-blind--among disabled minorities in general--between what might best be described as "fight" or "flight," necessitates enlightenment on the part of the reader concerning "prejudice." As defined by Allport,

"...Prejudice is a feeling, favorable or unfavorable, toward a person or thing, prior to, or not based on actual experience" (Allport, 1954, p. 7).

Implicit in this definition are both positive and negative prejudice. On the one hand, the former is demonstrated by behavior which is disparingly sympathetic, placating, and self-consciously benevolent. At the opposite pole, negative prejudice is expressed by attitudes toward the deaf-blind--and other disabled minorities--which are harsh,
critical, and unkind. Ironically, people tend in either case, on the basis of moral justification, to feel indignant when their erroneous perceptions and attitudes are challenged (Allport, 1954; Ryan, 1971). It is primarily for this reason that attempts to challenge prejudice through public education have, for the most part, proved unsuccessful. The wisdom in looking to public education as a means of change is questionable. Succinctly stated, this is due to the fact that the non-disabled person's prejudicial attitudes seldom prove destabilizing in his everyday interactions with those who are disabled. Contrarily, since any efforts on the part of the disabled to maintain their personal identity tends, as a rule, to promote interpersonal stress, acquiescence to the "status quo" seems expedient.

For those who are deaf-blind, or who have some other disability, the interpersonal stress, which is a salient factor of defying the status quo, though not always debilitating, is detrimental to mental health. This contention reflects the fact that albeit acquiescence may seem expedient, it deprives the disabled person of the "power" and "significance" which are major ingredients in self-esteem essential to a state of well-being (Schlesinger, 1978; Vernon, 1980).

It is interesting to note that a group of disabled subjects during informal interviews when asked what they felt could be done to alleviate the discrepency between
social and personal identity, perhaps not surprisingly, agreed that assertively to challenge the former was the most promising alternative. However, they themselves were reluctant to engage in such a risk-taking process. The individuals in question maintained positive personal identities, but did so through a withdrawal from confrontation which, to some extent, affected their social identities. It is noteworthy that one significant variable in study is that the participants had achieved a semblance of success. Consequently, the incongruence between social and personal identity was not as stressful as it would be for less successful individuals. Unfortunately, what the subjects of the study, and all disabled, need to realize is that from living assertively and empathetically comes a sense of personal power, through the knowledge that they have an impact on their environment (Stensrud, 1979).

With regard to "prejudice," there is a tremendously significant component which is seldom mentioned. What I refer to is the fact that stress is derived as much from the lack of positive conditions as from the presence of negative conditions. Implicitly this means that it is insufficient that people not experience prejudice (Kanner, Kafry, and Pines, 1978).

**Interpersonal Stress**

As stated earlier in this Chapter, the scarcity of research literature related to the process of interpersonal
stress is such that insight and the causal variables involved, remain elusive. That the need for such research exists is supported by reports that 75 percent of all illness is stress related (Brown, 1980). However, one attempt to ameliorate this situation is provided by Brown, through a detailed discussion of interpersonal stress and the psychological process by which it becomes debilitating.

Brown states that stress is a psychophysiological response to environmental stimulation. Albeit much of the stress response is physiological, the antecedent of a generalized stress response is cognitive. He maintains that worry is the cognitive process which causes the generalized stress response. The insidious aspect of this process is that

...the physical defense mechanism of the body, the biochemical and the physiological arousal mechanisms, are totally useless in defense against the kind of stress we mean when we talk about "stress" (Brown, 1980, pp. 85-86).

Equally relevant is his definition of social stress as

an unfavorable perception of the social environment and its dynamics (Brown, 1980, p. 90).

That is to say, social stress stems from the meaning one attributes to their environment through the expectations
applied to life situations.

The process of intentional perceptions which culminate in stress, as stipulated in Brown's theory, consists of seven stages. These stages are illustrated in the following hypothetical situation.

Suppose the family of a deaf-blind person all gather on a summer afternoon for a cookout. Albeit all family members have at least some experience in using the necessary communications skills, most find it tedious.

Stage 1. Expectation:
When the deaf-blind person attempts to engage five family members in conversation, only to be cut short after only a token greeting (because they find manual communication tedious), he/she will attribute their abruptness to rejection and expect the next relative to cut them short—and for the same reason. What occurs, succinctly stated, is a generalization of past experiences projected into the future as anticipation.

Stage 2. Perception:
In this instance, once the deaf-blind person expects to be rejected, he perceives any ambiguous experience as confirming those expectancies. If the next person with whom he comes in contact cuts them short because, let us say, of an emergency, he/she will project an expectation onto that person in the belief that being deaf-blind is at the root of the problem. Implicitly, once perception has
been confirmed, a pattern of expectation is established.

Stage 3. Worry:
As the deaf-blind person senses a difference between life experiences as he would like them to be, and as he perceives them, an effort is made to resolve the difference. Albeit such an effort is an attempt at problem-solving, thus basically desirable, the deaf-blind person lacks sufficient information to adjudicate the situation. As a consequence, he/she begins to worry about how unacceptable it is to be deaf-blind, or how unfairly he is being treated. Once the wheels have been set in motion, the problem-solving process continues in a vicious cycle, with little, if any, hope of arriving at a valid solution.

Stage 4. Uncertainty:
Lacking a self-enhancing solution to the original problem, uncertainty becomes a generalized expectancy. Rather than influence specific outcomes, worry causes the individual to develop a sense of ambiguity or instability which, in itself, is stress inducing. Since we all tend to rehearse cognitively an uncertain or unfinished situation—as a natural part of our problem-solving orientation—as in the mind of our deaf-blind subject, negative mental images begin to form. Such images create stress, just as relaxing images create relaxation.
Stage 5. Images of worry:
The third, fourth and fifth stages are interrelated.
Worry leads to uncertainty, which leads to

Stage 6. Rumination:
Which is defined as:

insidious, persistent preoccupation of the mind with pondering, speculating, imagining, and projecting back and forth in time (Brown, 1980, p. 102).

Obviously, when given free reign, rumination excludes the consideration of alternative possibilities.

Stage 7. Self-deception:
If the deaf-blind person in our hypothetical situation—or any person—becomes completely wrapped up in rumination he deceives himself into a self-fulfilling prophecy which creates a rigid expectation (bringing him back to square one) which is self-perpetuating and highly resistant to change.

The purpose of explaining Brown's theory in detail is to promote enlightenment into a complex process which, over time, culminates in inflexibility that restricts positive, self-enhancing action. Needless to say, such flexibility of response is essential in interpersonal interaction. This necessitates the cultivation of expectancies which enable the disabled person to perceive alternative
responses as possible and alternative environmental reinforcers as desirable. In our hypothetical situation, for example, if the sixth relative takes the trouble to return and explain the reason for his abruptness, the deaf-blind person will come to the realization that rejection is merely a possibility, not a certainty.

**Locus of Control**

The "locus of control" (i.e.) is an expectancy variable which, when measured on an i-e scale (Rotter, 1966), or a multi-dimensional scale (Levenson, 1972), provides insight as to the degree to which people perceive environmental reinforcements as being contingent upon their own behavior. Those who are "internals" consider environmental reinforcement to be contingent upon their behavior, abilities, and intentions. Contrarily, those who are "externals" consider such reinforcement to be contingent upon environmental variables such as fate or powerful others.

Although I have been unsuccessful in locating any studies which included hearing impaired or deaf-blind persons in the samples of disabled minorities, salient aspects of research results using other disabled minorities merit inclusion in this discussion.

1) "Locus of control" is generally considered an expectancy rather than a motivational variable.

Implicitly, those who were rated as "internals" were not
necessarily more highly motivated than those who rated as "externals;" and, expectancy had little bearing on the actual amount of control people had over their environment. Believing their behavior had a significant impact on their environment, "internals" behaved accordingly. "Externals" expected that their behavior was determined by their environment and behaved accordingly. In the final analysis, people developed their "internal" or "external" expectancies on the basis of their experience.

2) For most people, an "internal" locus of control is considered a positively valued personal attribute (Stern, Manifold, 1977). In view of the fact that internality nurtures expectancies which place responsibility for the life process on the individual, this is not surprising. Furthermore, since externality is indicative of the absence of self-enhancing expectancies, it does not seem unreasonable to hypothesize that it is stress inducing. Though by no means conclusive, Brown's theory lends itself to the support of such a hypothesis.

3) According to published locus of control research here members of disabled minorities were included in the sample, the following general assumptions are implicit: (a) The i-e scores of disabled subjects are significantly more external than those of non-disabled subjects; (b) as the severity of the disability increases, there is a concomitant increase in externality (Stensrud, Stensrud, and Stoddard, 1980, p. 13). On the other hand, when the
authors cited above conducted a study using mission disabled had a lower internal score than the non-severely disabled, it was higher than the non-disabled (Stensrud, Stensrud, and Stoddard, 1980, p. 15). On the basis of these results, the investigating researchers contend that the consideration of two relevant variables was overlooked in previous studies. Explicitly, the variables were (1) the stability of disabilities; (2) the presence of the same environmental expectations for both the experimental and controlled groups, with both groups, including subpopulations functioning successfully.

As stated earlier, I was unable to locate locus of control research where hearing-impaired and deaf-blind were included in the sample (including the research cited above). Interested in knowing what the results might be, and needing a project for a research requirement, a study was undertaken using a sample of hearing impaired college undergraduates. To test the hypothesis postulated in existing locus of control research that internality is inversely related to severity of disability, a modified version of Rotter's i-e scale (Rotter, 1966) was administered to thirty-one volunteers. The group ranged in age from 18 to 23, with the mean age of twenty. The composition of the sample population was

congenitally deaf ..........11
adventitiously deaf .......... 9
An analysis of the scores of the three subpopulations indicated that (1) the congenitally deaf and hard-of-hearing scored highest on internal mean response, with no significant difference between them; but, (2) the adventitiously deaf scored highest on external mean response, and there was a significant difference between this group's internal mean response and those of the other two subpopulations. With regard to the variable of stability of disability mentioned earlier, it should be noted that all of those who were adventitiously deaf had been deaf for at least six years at the time of the study. It should also be noted that all participants in the study were functioning in a college environment where approximately 98 percent of the student body had normal hearing.

These findings, though by no means conclusive, are certainly thought provoking when applied to the deaf-blind minority. This is especially true when we recall that the largest subpopulations within the deaf-blind minority consists of the adventitiously deaf and adventitiously blind. When considering this situation, it is essential to acknowledge the prevailing lack of insight, on the part of the general public, into the true nature of deaf-blindness. Given the circumstances just mentioned, it seems reasonable to ask just how much societal attitudes (and interpersonal stress) contribute to the externality of the adventitiously
disabled? In view of two suggested hypotheses (McDonald, 1971) the validity of this question is made poignantly clear. In summation they are:

(a) Those who attempt to overcome their disabilities have higher internal control orientations.

(b) Success in coping with difficulties which arise from the disability will change one in the direction of more internal control orientation.

At the beginning of this section, it was stated that the locus of control is an expectancy rather than a motivational variable. According to the results of another study (Large, 1982), motivation is listed as one of three variables which contribute to how an individual copes with disability in general, and stress inducing attitudes in particular. On the basis of the actual experience of those in the sample, as revealed in informal interviews, the investigator maintains that, even when exposed to negative attitudes within their immediate family (or others significant in their lives), a desire to retain a positive self-image provided the necessary motivation to cope.

Not surprisingly, in view of what has been said earlier in this chapter, the second variable related to the individual's coping pattern was success. That is to say, all participants in the study were—at least in the opinion of rehabilitation specialists—successful as well as well-adjusted. With regard to the present discussion,
it is unfortunate that in using the term "success," the investigator is not more specific as to the criteria by which success is measured. That is to say, it seems reasonable to wonder if rehabilitation specialists would, in defining "success," include the willingness assertively to challenge the status quo?

The third variable which emerged as relevant in the coping process of the disabled individual is "modeling." Those included in the sample indicated that they were strongly influenced by persons who possessed the same disability.

It is interesting to note that, with regard to the three variables mentioned, no significant difference of effects existed between those who were congenitally and those who were adventitiously disabled.

Suggested Remedial Measures

Modeling

As mentioned in the preceding section, providing the deaf-blind—or any disabled minority—with suitable models can enhance their ability assertively to challenge societal practices toward them which are stress inducing. What most people fail to realize is that, despite the fact that Helen Keller is justly credited with awakening an awareness within our society as to the desire, and potential, of the deaf-blind to function as normally as their limitations will permit, she is not a suitable model for the majority
living today. The primary reasons are: (a) Like "normal" people, many who are deaf-blind do not have the intelligence and/or intellectual abilities which Ms. Keller possessed; (b) Cause and onset of deaf-blindness--few are born deaf-blind. For the majority, it occurs during childhood, adolescence, adulthood, middle age, or even old age; (c) Lifestyle--given the circumstances of time, many deaf-blind realize a semblance of independence of which Ms. Keller only dreamed.

The fact that deaf-blind persons have strong opinions on this subject is made poignantly clear in an article which appeared in DISABLED USA. The material for the article was obtained during interviews with a group of deaf-blind individuals. With regard to the interviewees selected, it is important to note that all but one--and he is hard of hearing--became deaf-blind as adults. Equally significant, since they comprise the largest subpopulation within the deaf-blind minority, is the inclusion of two Usher Syndrome victims. One of these, Arthur Roehrig, who is Director of Hearing-Vision Impaired Programs at Gallaudet College, Washington, D.C., said in part;

... The Keller saga encourages some deaf-blind people to see themselves unrealistically. When deaf-blind people live alone far apart from each other, everyone sees them as prodigies. They are given a lot of praise and often think they are another Keller. When they meet other deaf-blind persons, they are often surprised to find their peers just as intelligent--and maybe even more so.
... When people hear about or meet a deaf-blind person, they feel sympathy and pity and say, "Oh, poor thing ... sorry." When they hear about Helen Keller, they say, "wow--great--wonderful!" There's a strong contradiction there ...

I never thought of comparing myself to Keller. We have different backgrounds. She lost both vision and hearing when she was young. In a more modern era, I was born deaf and lost my vision later in life. (Brown, 1982, p. ).

It would be to everyone's advantage if professions in particular, and society in general, would take a closer look at individuals such as Arthur Roehrig, when looking for suitable models. They can be found within every subpopulation of the deaf-blind minority. (Great diversity exists within the deaf-blind minority). For example, John became deaf-blind at the age of ten--the loss of hearing was not total. Now in his forties, he is a widower, lives alone and travels alone; and is a candidate for a Ph.D. On the other hand, Diane is a Rubella victim--i.e., her mother contracted German Measles during the early stage (first through fourth month--trimester) of pregnancy. She is retarded, deaf and has enough residual vision to read sign language and travel alone in her neighborhood. She lives with her parents and is an integral part of family life; and, at present, she is employed full-time in a sheltered workshop. Diane is in her early twenties.

Bill is a victim of Spinal Meningitis, which destroyed all of his hearing and most of his vision when he was thirteen years old. He resides in a home for the blind,
works full-time in a sheltered workshop. He enjoys traveling alone both in the city where he lives and distant parts of the United States. Like John (mentioned above), Bill uses speech for expressive communication. However, whereas John uses the Manual Alphabet or the Teletouch for receptive purposes, Bill uses sign language. This is due to the fact that Bill attended a school for the deaf after becoming deaf-blind, and had enough vision to learn and read sign language.

Jo is in her early forties. As the result of the fact that her parents were first cousins, Jo and an older sibling were born blind. She was in her mid-thirties, divorced, the mother of two children, and holding down a full-time job when she became severely hard-of-hearing. She was sent to a rehabilitation center where she was taught the Manual Alphabet and mobility techniques needed to travel alone as a legally deaf-blind person. After training, she found employment as a teacher-aide and found an apartment near the school.

Frank is in his seventies and is a victim of Usher Syndrome. He received his education in a residential school for the deaf. He was hired as a teacher at the same school, and remained in this position for more than 30 years. Visual deterioration was slow; at the time of his retirement he was almost totally blind. Since retiring Frank has married a deaf-blind woman whom he met at a housing development for disabled senior citizens. Both he
and his wife are active in the deaf-blind community and enjoy crafts and taking care of their apartment.

Suffice it to say, the list could go on and on. However, I believe enough information has been provided to convince the reader that suitable models are not difficult to find.

Stress Management Training

There is a need, on the part of the counseling professionals to develop strategies to help the deaf-blind to relate effectively to those with whom they come in contact. Since, as has been pointed out earlier in this Chapter, there is often a conflict between the deaf-blind person's self-perception and the way others perceive him/her, assistance is essential in developing the skills assertively to challenge the latter. Assertiveness training is a widely used counseling method with normal populations, and with those suffering from a wide range of psychological disorders (Heimberg, Montgomery, Madsen, and Heimberg, 1977), but no studies have been reported using deaf-blind participants. Interestingly, reports of studies where other disabled minorities were included indicate that such training is usually effective (Mischel, 1978). Of equal significance it should be noted that the literature available reveals a need for more research on the effects of assertiveness training as a counseling technique with segments of the disabled population (Chambless and
Goldstein, 1979). This would appear to be especially true of the more severely disabled, such as the deaf-blind.

Assertiveness training is a behavioral based communication program conducted in a group setting. Role playing and discussion are utilized in teaching the participants to express rights and preferences without violating the rights of others. It stands to reason that, when participants are deaf-blind, groups, for best results, should be kept small; and, careful consideration should be given to the communication skills of the deaf-blind group members. Implicitly, this calls for extra efforts on the part of program coordinators. However, in view of the limitations inherent in deaf-blindness, possible benefits should outweigh any necessary measures for successful implementation of such programs. In support of this contention, it is necessary to emphasize that deaf-blind individuals tend to become dependent on social agencies and significant others in their lives due to a) lack of confidence; and b) because social agencies and families often encourage dependence (Thomason and Clifford, 1972). Furthermore, since deaf-blind persons, like others who are disabled, often having difficulty obtaining and/or holding jobs, as a result of dependency problems (Neff, 1968), assertiveness training offers a solution which merits investigation. Even when dependency is not a factor, there are deaf-blind persons who lack the ability to deal assertively with their interpersonal relationships, thus
finding it difficult, if not impossible, to establish healthy, self-enhancing relationships (Neff, 1968).

Counseling

In Chapter II of this text, it was stated that the number of counselors with the necessary communication skills to assist deaf-blind individuals and their families is extremely inadequate. This applies to other disabled minorities as well, and covers the total spectrum of the counseling profession. For example, guidance and rehabilitation counselors are excellent sources of interpersonal training, but the number of such professionals who specialize in services to the deaf and hearing impaired leaves much to be desired (Vernon and Hyatt, 1981). Ironically, though many hearing impaired individuals have been mainstreamed at every level of our educational system in recent years, few counselors are available to assist the vast majority with their personal problems or career planning. The significance of this shortage as it applies to the deaf-blind minority is derived from the fact that a fairly large number of the victims of the Rubella epidemic of 1964-1965 have also entered the mainstream.

Psychological Testing

In all areas of counseling, psychological tests are often the criteria used in assessing clients' personality, interests and abilities. For this reason, it is the
contention of this writer that there exists, on the part of psychologists and researchers, a need to re-evaluate and, when necessary, modify so-called "standardized" tests, with a view to the consideration of variables unique to the deaf-blind minority. Until such measures are undertaken, many measuring instruments currently in use, as applied to deaf-blind clients, lack validity. By way of clarification, consider the following illustrations:

Example 1) Personality Inventory:

Item: I am afraid of the dark. yes no
Item: I am afraid to be alone in the dark. yes no

Suffice it to say, that for the congenitally blind person who has never seen the light of day, such items are ludicrous. The same would apply to the majority of those who became blind in childhood. On the other hand, since night-blindness is usually the first area of difficulty experienced by an Usher Syndrome victim, the dark or being alone in the dark is, for many, frightening, if not terrifying. Under such circumstances it seems reasonable to question the validity of items like those above in assessing the personality traits of deaf-blind individuals.

Example 2) Interest Inventory:

Item: Would you like to be
(a) a truck driver
(b) a concert musician

It is not unusual to find deaf-blind persons who were
accomplished musicians prior to the onset of deafness. However, I know of no congenitally deaf individuals, either through acquaintance or inquiry, who are musicians. Since the largest subpopulation within the deaf-blind population are victims of Usher Syndrome—thus, congenitally deaf—and they may enjoy singing groups, pursuit of a career as a concert musician would not evoke much interest. On the other hand, many Usher Syndrome victims owned and drove an automobile before the onset of blindness—and even trucks. From the psychological perspective, what is the true nature of the value of such items as applied to a deaf-blind person's interests?

Example 3) Intelligence Tests:

As a teacher of deaf-blind children, I was asked, on occasion, to administer intelligence tests to my students. The following item, and the student's response illustrates the need for more realism in the design of such items. The student in this case was twelve years old. He had enough residual vision to see light and shadows; and, he was severely hard-of-hearing.

Item: When examined under a microscope, how many points does a snowflake have?

Student: "You can't do that!"

Teacher: "Why?"

Student: "It would melt."

There remains one paramount factor which must be
considered in the design of any verbal measuring instrument which is to be administered to deaf-blind persons. The factor to which I refer is language structure. This is necessitated by the fact that, for many who are deaf-blind, English is a second language, with sign language occupying the position of first language.

Conclusion

In the final analysis, the factors mentioned in this chapter which contribute to interpersonal stress can best be changed through the efforts of the deaf-blind (and other disabled minorities) themselves. For instance, it is incumbent upon them to be mindful of the fact that almost all of those whom they encounter are handicapped by their unfamiliarity with people who are physically different from themselves, and consequently, uncertain as to how to react. Implicitly, it is necessary for deaf-blind persons to recognize and accept this "incapacity" of the non-disabled and to know how to cope with it. This requires patience and understanding in dealing with the often clumsy efforts and the unintentional insults they may encounter in their interactions with nondisabled (Thomason and Clifford, 1972, p. 222). On the other hand, professionals--and the general public--need to become sensitized to the unique aspects of deaf-blindness, which means they must be willing to learn.

For obvious reasons, deaf-blind individuals have much to gain through counseling through a) assistance in coming
to terms with their interpersonal expectancies, b) training in the skills which will enhance their interpersonal relationships, and c) encouragement to utilize such skills.

The following suggestions are offered in the hope that they may be of value to the reader in their association with a deaf-blind person.

1) When approaching a deaf-blind person, a simple touch—on the hand, or shoulder, etc.—is essential to enable him to be aware of your presence. When your contacts extend over a period of time, a simple clue—a favorite piece of jewelry which you wear such as a ring, etc.—or a sign—such as a name sign—will enable most deaf-blind acquaintances to identify you.

2) Avoid making hasty judgments concerning a deaf-blind person's intelligence or abilities, even when, by normal standards, they seem limited.

3) Remember that, like all human beings, each deaf-blind person is unique. Consequently, avoid trying to put them into a mold—another Helen Keller, or another Arthur Roehrig, etc.

4) Avoid any attempt on your part to impose your ideas—opinions, ethics, politics, religious beliefs—on a deaf-blind person. Preferably, encourage him/her to express his own ideas, providing feedback as needed to be sure you are both on the same wave length.

5) Encourage him/her to use initiative and to actively engage in decision making.
6) When you are using an interpreter, or other people are present, be sure the deaf-blind person knows what is happening. If you must interrupt them, or leave him abruptly, make an effort to explain the reason.

7) If you must move something--e.g., a chair, purse, coat, etc.--be sure the deaf-blind person know it has been moved, and to where.

8) It is best to ask rather than assume your assistance is needed--to cut meat, unlock a door, etc.

9) When showing a deaf-blind person to a seat, when possible, place his hand on the back of it, or on the seat itself.

10) If you have occasion to guide a deaf-blind person, let him/her take hold of your arm--usually above the elbow.

Interpersonal stress can best be minimized when a deaf-blind individual (or anyone with a disability) has a feeling of usefulness as opposed to helplessness or dependence; respect rather than condescending benevolence or pity; a positive self-image devoid of self-pity.
Chapter V
COMMUNICATION

Introduction

The phenomenon of "isolation," as experienced by deaf-blind persons has been mentioned several times in this text. Summarily it has been stated that, a) there are two types of "isolation," i.e., isolation from knowledge and isolation from people, and, b) the underlying causes are (1) limited language development, (2) inadequate communication skills and/or (3) lack of opportunity for interpersonal communication. The psychological implications posed by any of the above mentioned factors are of profound significance.

The student of psychology is doubtless aware that deaf-blind individuals do not have a monopoly in the area of interpersonal communication deficiencies. The primary difference however, in the problematic situations experienced by the so-called "normal" population, such as the "generation gap," or communication breakdowns between partners in a marriage, are psychological in origin, as contrasted with the deaf-blind person's limited language, inadequate communication skills or opportunity to relate to others. Implicitly, this point presents a different type of challenge to a counselor in that he/she must recognize the necessity for a) a knowledge of the various communication modalities currently in use by the deaf-blind minority; b)
the desirability, from the professional perspective, of achieving at least a measure of facility in one of the most widely used modalities; c) acknowledgement of the fact that communicating may take longer. At times it may be necessary to enlist the services of a qualified interpreter. Problems experienced by deaf-blind persons in interpersonal communication can be alleviated through the availability of individual, family, and marriage counseling. Therefore, with a view to providing insight and encouragement, the objective of this Chapter is twofold: 1. to discuss various communication modalities; and, 2. to share with the reader comments and experiences of several deaf-blind persons related to the subject of communication.

Communication Modalities

The communication modality used by a deaf-blind individual is dependent of two variables discussed in Chapter One. Specifically, the variables are: etiology and onset of disability. The congenitally blind-adventitiously deaf, who have usually developed tactile skills through the use of Braille, will, more than likely, receive training in the one-hand manual alphabet, commonly known as fingerspelling. On the other hand, the congenitally deaf-adventitiously blind individual may, or may not know, fingerspelling. However, those who are familiar with it are used to visual communication which
means they will need training in the mastery of tactile communication. Since a large segment of this subpopulation have sign language as a first language, a major adjustment will be essential in the process of mastery of tactile sign language. When members of this subpopulation are educated in an "oral" school, they will receive training in speech, lip reading, and possibly fingerspelling and/or sign language--this is known as "Total Communication." Unfortunately, unless their residual vision is sufficient, those with strictly "oral" skills--i.e., lip reading--will face the greatest challenge with regard to the acquisition of tactile communication skills. Furthermore, unless residual vision remains sufficient to enable persons in this subpopulation to read large-print, learning Braille affords the only avenue which will prevent "isolation" from knowledge. For many, even when etiological factors are indicative of visual deterioration, counselors will find that there is a psychological resistance to training in Braille. The adventitiously deaf-blind possess speech for expressive communication, but they too will face the challenge of mastering a tactile communication modality.

**Printing in the Palm**

This method consists of printing the letters of the alphabet in capitals (or block letters) in the palm of a deaf-blind person. Logically, this method affords a practical beginning for use with adventitiously deaf-blind, congenitally deaf-adventitiously blind, and some
congenitally blind and adventitiously deaf. In the experience of this writer, it appears to be more acceptable psychologically in that it is closely associated with the world of printed matter. From the practical vantage point of view, however, few individuals achieve the level of speed attainable through other methods.

There are variations of this method. That is to say, rather than the palm, some deaf-blind persons read print (and in some cases script) written on their arm or back. One deaf-blind person of my acquaintance has the speaker guide her hand, in which she holds a pencil, across a sheet of paper.

The One-Hand Manual Alphabet (Fingerspelling)

For the congenitally blind-adventitiously deaf, fingerspelling is the most widely used communication modality. Over time, with practice and consistent use, users of this method can communicate at the rate of 60 words per minute. Historically, this system was orginated for use in a monastery where the monks were subject to a vow of silence. Nowadays, it is known by many deaf individuals and interpreters of the deaf. However the configurations are made in the air. Since tactile fingerspelling involves a different technique, patience and practice is required on the part of the congenitally deaf-adventitiously blind and interpreters of the deaf in making the necessary adjustment. Not surprising, many interpreters of the deaf find tactile fingerspelling
fatiguing. Such fatigue can be minimized if both the deaf-blind person and the person with whom he is communicating rest their elbows on a smooth surface, such as a table or desk. Preferably, the deaf-blind person's hand (usually, but not always the left) is extended straight up, with the palm facing the speaker.

There are occasions, when it is more convenient for the deaf-blind person to extend his hand, palm up, enabling the speaker to fingerspell into the upturned palm. This procedure is often more convenient when walking or riding in a car. A third procedure involves having the deaf-blind person "read" by placing his hand over the back of the speaker's hand. In this case, the speaker's palm is pointed down. It is, needless to say, advantageous if a deaf-blind person is skilled in all three procedures.

**Tadoma**

There is a small subpopulation within the deaf-blind minority who have received long, arduous training which enables them to read lips by touch. Two persons of my acquaintance who use this method became deaf-blind as children and use speech for expressive communication. Two others can use Tadoma for receptive communication, but must rely on another modality for expressive purposes, because they are mute. Surprisingly, albeit one might assume that Tadoma would be the most popular method, especially for use by hearing persons with limited (if any) facility in deaf-blind communication modalities, such is not always the
That is to say, deaf-blind persons who use Tadoma maintain that many people exhibit embarrassment or discomfort when their lips or throat are touched.

The Tellatouch

For those deaf-blind persons with a knowledge of Braille, the Tellatouch is a popular means of receptive communication. It is a portable device which resembles a miniature typewriter. The Tellatouch utilizes a keyboard which is comparable to the standard typewriter keyboard. There are, however, two major differences. First of all, it has three full rows, rather than four full rows. The missing row is that of the upper row on a typewriter, which contains numbers and symbols. The second difference is the presence of three keys on either side of the space bar. Each of these keys represents a dot of the Braille cell, and consequently, they are only used by persons who know how Braille is written.

When the speaker presses one of the print keys on the Tellatouch, the corresponding Braille letter appears under the deaf-blind person's fingertip. By pressing combinations of the six-keys—three on either side of the space bar—the same results are achieved by the speaker who knows Braille. Typing skills are not essential. Anyone who can read the print keyboard and press the keys can communicate via a Tellatouch. It stands to reason, however, that a person with typing skills will, most likely, achieve a faster pace. One area of frustration to
deaf-blind persons is that some people hesitate to use the Tellatouch—and even printing in the palm—because they are self-conscious about their spelling. Imperfect spelling—which may not even be noticed—is of minor importance in comparison with a willingness to communicate.

Sign Language

Since victims of Usher Syndrome comprise the largest subpopulation within the deaf-blind minority, sign language—both visual and tactile—is the most widely used communication modality currently used in the United States. Above and beyond the time and effort required for mastery of sign language by other subpopulations within the deaf-blind minority and other interested persons, there is considerable controversy as to which form of sign language should be taught. For example, Signed Exact English (SEE) was developed for use in school by children. As the name signifies, it utilizes the components of the English language. A second form of sign language is Pigeon-Signed English (PSE), which is a modified form of the English language. However, a third form, the one which has the strongest support at this time, is American Sign Language (ASL). Succinctly stated, ASL is a unique language which has very little in common with written or spoken English. As a result, for deaf-blind and deaf persons who grow up using ASL, English is a second language. Furthermore, one feature of ASL which makes it
difficult for congenitally blind-adventitiously deaf or adventitiously deaf-blind to learn, is that it encompasses gestures which are strictly visual.

It is imperative to stress that the preceding comments are in no way meant to discourage professionals or anyone else from learning sign language. In point of fact, there are some certified interpreters among the counseling profession; there is a need for more. It should also be emphasized here that any form of sign language can be used in tactile signing. On the other hand, some deaf-blind persons retain enough residual vision to sight-read sign language. There may be a narrowing of the visual field, the "tunnel vision" experienced by victims of Usher Syndrome; or a distance at which focus is best, as/or post-cataract victims or those who are myopic. The wise person with a restricted field of vision will hold onto the wrist of the person signing to assist him in keeping the signs within range. In such situations, it is advisable for the signer to keep signs small and close to the deaf-blind person's face.

Speech

There are deaf-blind persons with enough residual hearing to communicate on a one-to-one basis using speech. Of course, how well they do will depend not only on the amount of hearing, but on the quality of the other person's speech, and the noise level. There are also some who either had hearing at one time, or received speech
training, who use speech for expressive purposes.

It is of the utmost importance that any deaf-blind person who has speech be encouraged to use it. Since the muscles used in speech are the same as any other muscles in our body, they must be exercised, or they become weak and flabby. Once these muscles begin to deteriorate, the deaf-blind person's pronunciation becomes blurred. Additionally, many deaf-blind persons will appreciate aid when experiencing difficulty in pronouncing a word. However, to avoid frustration it is helpful if the speaker can either compare the difficult word with one already known, (e.g., "m-ime" is pronounced like "t-ime;" the second syllable in "clien-tele" is pronounced like "tell"), or spell it phonetically, (e.g. "pneumonia" would be spelled "numonia;" "knead" would be spelled "need").

One problem experienced by most deaf-blind persons who use speech for expressive communications concerns the matter of modulation. For example, one will need to speak louder in a crowded restaurant and softer on a quiet street. For some deaf-blind people, it is extremely helpful if they know, when entering a room for the first time, if it is a large or small room. In any situation however, deaf-blind persons have a system, of which their friends should be aware, in the form of a hand gesture, or several of them. One such system, as discussed by the late Richard Kinney (who was deaf-blind) in a text which he wrote for the Hadley Correspondence School for the Blind,
entitled INDEPENDENT LIVING WITHOUT SIGHT AND HEARING, consists of a simple finger stroke upward on the shoulder or wrist to mean "speak louder," and a downward stroke to mean "speak softer." A second suggestion made by Kinney, which can save misunderstanding and needless confusion, is to use a slight, continuous pressure on the deaf-blind person's hand to let him know someone else is speaking, or some other interruption has occurred.

Salient Aspects of Deaf-Blind Communication

Psychological Factors

Counselors of persons who are newly deaf-blind and experiencing difficulty may find, as this writer has, that the primary problems stem from the individual's resistance, and often the resistance of significant others in their lives, to learning any communication modality which necessitates the acceptance of deafness or deaf-blindness as an indisputable fact of life. One client, a woman, was employed as a secretary when she lost her sight as the result of Retinitis Pigmentosa. She received training in mobility, daily living skills, and was taught Braille. Although she was never again gainfully employed, she led an active life within her family circle and among the blind community. At the time she was referred for counseling, she had been deaf for five years. There were periods of complete disorientation as she sat alone for days on end in her apartment. Effort to persuade her to learn
fingerspelling were futile. Although she was proficient in the use of Braille for reading and writing, she could not master the Tellatouch machine. She used speech for expressive communication. However, she and her family insisted that printing in the palm was the only method acceptable to them. In our first session she stated that she could not relate to "really deaf-blind persons;" and, that she "missed the hearing world." It was impossible for her to believe that this writer was a "really deaf-blind person." The only alternative with regard to communication was to endeavor to help her acquire greater facility in palm-printing and to encourage her to at least master the Tellatouch so that she might help others whose situation was similar to her own.

A second client who is a widow with married children, was hard-of-hearing as a child. She was trained in an oral school, and as her hearing deteriorated, she came to rely exclusively on lipreading for receptive communication, speech for expressive communication. She was referred for counseling because she had attempted suicide. Her vision has deteriorated to the point where she can no longer rely on lipreading. Furthermore, she suffers from night-blindness; it was while alone at night in her home that she attempted suicide. As counseling sessions progressed, she stated that she couldn't live as a totally deaf-blind person. She felt her children rejected her, when in reality, they were as upset as she was by their inability to communicate
with her. She agreed to learn fingerspelling, but she was adamant in her refusal to suggest this as an alternative means of communication for her family. Opportunity was provided for her to meet other deaf-blind persons. However, unless they have speech, and she can understand them, a situation which becomes more and more unlikely with the passing of each day, she takes the view that they are not intelligent.

A third client who is deaf and losing her sight also relies on lipreading skills. One married offspring lives nearby and she sees the others regularly. She refuses to learn any form of deaf-blind communication. Her philosophy is that something, like a miracle, will enable her to relate to the hearing world the same way she has always done. One positive factor is that she was willing to use fingerspelling very slowly, but accurately to communicate expressively with me.

Counseling clients, such as the three mentioned above, is a challenging but often frustrating experience. It is the belief of this writer that the adjustment to deaf-blindness, with all its ramifications can be ameliorated in many instances through family counseling. For example, the first client mentioned, received no support from her family with regard to acceptance of the need to acquire communication skills. They were as resistant to acceptance as the client herself. The second client, who was able to express her feelings of
fear and neglect on the part of her offspring, would not
discuss those feelings openly with them. When asked to
visit them, more often that not she refused; they live
several hundred miles away. On the rare occasions when
she accepted their invitation, she returned to complain
that she felt isolated because she could not take an
active part in family conversations, that she felt
insecure in a different environment, that she did not
feel needed. She concluded that it was best for her to
stay at home and endeavor to persuade the family to come
to her. The family is puzzled and confused by her
reluctance to visit them. The client is unwilling to
discuss her situation with them, preferring to use the
excuse that it is better for her health to stay at home.
The third client and her offspring could also benefit
through open, honest discussion.

Speech/Intelligence

There are many people in our society who equate the
inability to speak with lack of intelligence. In point
of fact, there are many highly intelligent mutes among
the deaf and deaf-blind minorities. The following
remarks by an Usher's Syndrome victim is indicative of
the strong feelings such individuals have on the subject.

... Stories written about deaf-blind people
usually portray those who can speak and
suggest that this accomplishment shows how
intelligent they are. But, speaking is a
matter of ability, not intelligence. If ten people try walking across a rope, some do it without falling. Others will fall, no matter how much they practice. Still, they are just as intelligent (Brown, 1982, p. 18).

The reader may recall that Art Roehrig who was quoted in chapter IV. is mute. At this writing, he is working on the Ph.D. degree at Gallaudet College for the deaf, in Washington, D.C.

Another deaf-blind man who also has something to say on this subject is Rod McDonald. He is legally blind, and attended the Perkins School for the Blind, in Watertown, Massachusetts. Rod's hearing began to deteriorate while he was attending college. By the time he had completed college he was classified as deaf-blind. He used speech for expressive communication and prefers fingerspelling for receptive communication. However, he can also use fingerspelling and sign language for expressive communication with deaf or other deaf-blind persons. Currently, Rod is employed as a computer specialist with the Department of Labor. His comments read as follows:

Intellectually (Helen) Keller has probably never been surpassed. But there are many other areas in which deaf-blind people have become proficient. While she could speak and be understood, her speech was never easy to understand. There are deaf-blind people who have done better, and there are better techniques for teaching speech to deaf-blind children (Brown, 1982, p. 19).
About Tactile Communication and Acceptance

Logically, the individual who is fluent in sign language and/or fingerspelling at the onset of deaf-blindness should have an advantage in the area of interpersonal communication. Since both of these communication modalities were devised for use by the deaf minority, who "read" it with their eyes, those deaf-blind persons who retain enough residual vision to continue receptive communication in this manner usually have the greater advantage. One factor which supports this contention is the fact that most certified interpreters (and other professionals who know sign language) are not trained in the techniques of tactile communication. Consequently, even when a deaf-blind person possesses excellent tactile skills in sign language and/or fingerspelling, they often experience the same "isolation" from people and feelings of rejection as do deaf-blind persons who lack these skills when deaf-blindness occurs.

In an effort to clarify the points made in the preceding paragraph, I would like to share with the reader excerpts from an article by an Usher's Syndrome victim, which appeared in THE DEAF AMERICAN. Author Jack Wright, was educated in a residential school for the deaf where he formed deeply meaningful ties with the deaf community. At the age of twenty, he began to experience night blindness and started to lose his
peripheral vision. In part his article reads:

Over the next 15 years, my vision continued to deteriorate to the point where I could no longer ignore it. I was working as an engraver and I started missing words when I was reading. The boss noticed that I was having problems measuring, and sent me to an eye doctor. The doctor told me I was legally blind and that my vision would get worse. ... I felt my life was starting to go down the drain when the doctor told me I was legally blind. When my boss got the doctor's report, he told me to start looking for another job, because I would be fired in 30 days.

I started to worry about what would happen to me. ... In addition, I had a wife and two small children to support, and I had to find a job.

Over the next few years, I started having problems reading signs (meaning sign language); I often had to touch the person's hands to follow what they were signing. I also could not recognize faces or read regular print. The only part of the newspaper I could read was the headlines. I felt my means of obtaining information slipping away. I felt more and more cut off from the world.

In 1975, I had a cataract operation which improved my vision somewhat. I could now read large-print and could read people's handwriting if they used a dark pen. That same year I was divorced and went home to live with my parents. I was very uncomfortable with this situation because I had always been independent. But I did not know how to travel alone, cook, or shop, and I had no knowledge of Braille. My vision began to deteriorate again and I became very depressed. I knew I had to do something, so when a (rehabilitation) counselor suggested I try a new training program for the deaf-blind, I packed my bags and left.

... There I studied braille, cooking, cane travel, and learned to play games that had been adapted for the visually handicapped, such as SCRABBLE. I also improved my ability
to read signs by touch. I am very happy I learned all these things, especially Braille, for I now feel I am no longer cut off from the rest of the world. I can read Braille magazines and books, and keep up with what is going on in the world. I also have a Braille TTY, so that I can now communicate with others by telephone.

I am independent again, but I do have some problems. Some deaf people avoid me. They are afraid I will become dependent upon them, and are unsure what to do in such a situation. They are used to using their sight in communication with others, and they cannot understand how a person who is blind can communicate in signs.

In social situations, I cannot see who is nearby, so I can't approach a person and start a conversation. I must rely on other people to come up to me and introduce themselves or other people. Introductions are very important to me because that is the only way I can meet new people. This is the most difficult problem I have socially ... I love to communicate, get information and share ideas.

Whenever a person approaches me, it is important that they give me their name, or their name sign, so that I know with whom I am chatting. ... It is hard for some people to believe that I can understand as much Sign Language by touch as I once did by sight, but this is true. ... Some people use only fingerspelling when they communicate with me. While there are deaf-blind people who prefer to use only fingerspelling, I like to use Sign Language because it is the language I grew up with and the method of communication most comfortable for me.

Another problem is that many people feel I will injure myself in a strange place and are afraid to have me go with them. ... Some of my old friends continued to include me in their activities even after I lost my vision. That is because they had had some experience with other deaf-blind people, and were not afraid to stay with them. But others started worrying about my mobility--how to tell me about steps, how to guide me to a chair, and so on. I explained to them how to help me, and
they quickly learned how to guide, and found it was not so difficult after all. A deaf-blind person with the proper training and experience in using mobility techniques has very few problems getting around.

... I feel confident traveling by bus, train or plane. I write notes to ask people for help if I need it. I can tell from their reactions what their emotions are. If they seem confused, or do not understand, then I look for another person. ... I ask people to print in the palm of my hand with their finger, or I use the Tellatouch machine for receptive communication. When I take the bus home from work, I show the driver a card that tells him where I wish to get off, and he taps my leg at the right stop. I just have to trust him. Sometimes, of course, things will go wrong, just as they do for anyone. But the more experience I get the fewer the problems, and the better able I am to deal with them.

... I receive one weekly news magazine and several monthly or quarterly magazines which come out in braille. These magazines focus on the needs of blind people, with almost nothing included on deafness or deaf people. Deaf-blind people are not informed about what is going on (in the Deaf Community) since very little information is available in braille or large-print. The only way I can learn about ... the Deaf Community is to ask friends.

... Deaf people know amongst themselves what is going on in the Deaf Community, but a deaf-blind person has great difficulty finding out. Many deaf-blind people stay home alone simply because they do not know what is going on.

For ten years I was an enthusiastic member of a bowling league for deaf people. I did very well and had some of the highest scores until my vision deteriorated. My scores started to get lower and lower, and I felt the other team members would blame me for a low average score, so I quit. This past year I joined a bowling league for blind people. I really enjoyed the bowling, and the blind people were very nice, but there was no one there with whom I could communicate directly, so I quit in frustration. I feel really stuck in the middle--my score is not really high enough to compete in a league
for deaf people, and I am often unable to communicate with blind people. I find that this carries over into other areas as well (Wright, 1982, pp. 26-30).

Like Jack Wright, many deaf-blind persons experience the feeling of being "stuck in the middle". To a point, their situation is comparable to the man without a country. On the one hand, even though they possess the necessary skills to communicate with deaf people, gaining acceptance within the deaf community, or maintaining their membership in it—is not an easy matter. When, on the other hand, they aspire to maintain or gain membership in the blind community, the deaf-blind person becomes discouraged or frustrated because the vast majority of blind persons cannot communicate directly. The fact that a blind person uses braille should be sufficient for direct communication via the Tellatouch machine. Implicitly, in both situations, the difficulty many deaf-blind persons experience in their efforts to find acceptance in the deaf or blind community is, with some exceptions, not related to the absence of an avenue for direct communication. The heart of the matter is that deaf people and blind people in general, like the nondisabled in our society, are handicapped in their ability to accept deaf-blindness by misunderstanding and stereotypical attitudes. In the final analysis then, there are psychological factors
related to gaining acceptance which have nothing to do with the deaf-blind person's ability to communicate.
Conclusion

If the first objective of this Chapter has been achieved, the reader should now have a more realistic perspective concerning deaf-blind communication modalities. There are a variety of methods which can be used; it is important to emphasize that the level of language development and the choice of communication method(s) is an individual matter.

Deaf-blind persons should be encouraged to acquire proficiency in more than one communication modality. Preferably, this should include a method, such as palm-printing or the Tellatouch, which does not necessitate special training for those with whom they come in contact. Furthermore, it is incumbent upon the deaf-blind person to be supportive and patient with those who are slow, or trying to master a new communication skill, such as fingerspelling or sign language.

It is equally important for those who come in contact with deaf-blind individuals to deal realistically with any inhibitions they may have concerning tactile communication. Remember that direct communication, even when slow, is as important to a deaf-blind person as it is to anyone else. Should you meet a deaf-blind person who uses printing in the palm or forearm or some other part of the body he/she may be newly deaf-blind, or may not be ready psychologically to accept deaf-blindness. Direct interpersonal communication which is strictly dyadic, is as
vital to the mental well-being of a deaf-blind person as it is to any other human being. Ethically, in the counseling situation, it provides the deaf-blind client with the same rights of privacy and confidentiality afforded other clients.
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CHAPTER 2


CHAPTER 3


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CHAPTER 4


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CHAPTER 5

